



FACULTEIT PSYCHOLOGIE EN
PEDAGOGISCHE WETENSCHAPPEN

Participation of children with severe communicative difficulties in inclusive education and society

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Proefschrift ingediend tot het behalen van de academische graad
van Doctor in de Pedagogische Wetenschappen

2011

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Orthopedagogische Reeks Gent, nr. 39, 2011

ISSN: 0779/1046

D/2011/6585/39

Vakgroep Orthopedagogiek

J. Guislainstraat 47, 9000 Gent

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Dedicated to Kobe.

*En als ik dood ga, treur maar niet
ik ben niet echt weg, moet je weten
het is het verlangen dat ik achterliet
dood ben ik pas als jij me bent vergeten.*

Bram Vermeulen



"Monsterfile", work by Caroline Callens, the mother of Kobe, 2010

Acknowledgements

Each time I receive a thesis from one of my colleagues, the first thing I read, are the acknowledgements. Now it is my turn and I must say, this is not easy. So please be gentle if I miss some people or do not use the most eloquent language.

With wonder, I look back at my journey since I graduated as a Master in Orthopedagogics. I tumbled into working life, without clear expectations or ambitions. Pedagogy begins and ends with servitude. Working with other people always inspired me. I know very well that I owe this thesis to a lot of people who made me strong and courageous enough to push my 'stone' all the way up... So I would like to name them and give something back.

First of all, Sofie and her parents...

Sofie, you are graduating this year from secondary school. I look at you and I see a woman, a woman with power who is looking anxious but hopeful to the future ahead of her. I am very proud of you.

Rita and Toon, you learned me so much about becoming a parent. I saw you two, together, going to the first parent evening, sitting at Sofie's bed, letting her go to the scouts and sleep for the first time not at home... A lot of very small, critical incidents cross my mind, much more than I can write about here. You two are very special in pulling people close to Sofie and make them feel responsible to take their share in the educational process of your daughter.

I want to say a very special 'thank you' to Kobe, Karel and Heleen and their families. These children are very close to my heart. They present(ed) themselves as adventures, make me think very hard. I am always very honored to encounter traces of them in my way of thinking and living. If I know what inclusive education can do, it is because of them and the web of connections where they are part of.

There are many children, mothers, fathers, support workers, teachers, principals and special educators that I need to acknowledge. I talked with them, I observed them, I listened to them, I admired them, I worked with them and each time a little piece of them kept sticking on my own body. I cannot say all of your names, but know that with everyone of you, I recall very special moments of togetherness.

For this work, I entered an academic world. Geert Van Hove welcomed me.

Geert, I learned from your way of working together with people. I could fall back on you to share, think and reflect. You showed me the importance of praxis and what it can mean in the daily lived experiences of people. You gave me space and time to discover my own path in this thesis and believed in my capabilities. Know that I am very grateful for that. In our journey, from a student in your lesson until now a member of your team, I always appreciated your positive and constructive way of working.

I have to thank the three gentle men who accompanied me as my guidance commission: Patrick Devlieger, Michel Vandenbroeck and Phil Bayliss. I often had the feeling, after a meeting, I was sent into the desert with three bananas. After a while, it became clear you gave me strong directions to build further on. I want to say an extra 'thanks' to you, Phil. You are a teacher in heart and soul and I always loved to listen and discuss with you. It lightened my fire.

In the working towards this thesis, Julie Allan also played an important role for me. I could work six months at her University. As a family, we have very warm memories of that period together with Lise in Stirling, but there is more. My stay there gave me a lot of inspiration, while I was writing. Julie, I enjoyed our conversations in the coffee bar, they sparked me with insights. The time and space, hidden away with books, articles and laptop gave a boost to my confidence and my work.

I would not survive in the academic world without 'bridges' to 'real life'. I have to thank two movements of people I work closely together with and in which I am personally engaged.

Our New Future, the self-advocacy movement of strong women and men. I saw people grow in that environment, much more than I could contain. People are unbelievably strong to find their way in life and face injustice. They use their 'secret power', resilience. We work together side by side, core members and advisors.

Parents for Inclusion, a movement of parents where I've learned very literally that change doesn't grow fast like grass, but rather slow, like the roots of a tree, you need lots and lots of patience. I see this in the processes of your children but also in your never ending battles to get recognition for inclusive education in our society. Thank you, we need pioneers like you and your children.

I know my allies. I could always depend on these good colleagues and friends.

Elke and Inge, I spend hours and hours with you two, talking about Kobe, Sofie, children and situations we worked in. A lot has changed since we were (only) young and raving, but I will always cherish our connectedness and authentic engagement.

Thank you, Kathleen. I started to work with you on the research project on 'inclusive education'. It was very exciting and we worked very hard to put inclusive education on the map in Flanders. The way you delivered your phd, showed me your perseverance once more and gave me confidence for my own work.

I have to say a very genuine 'thank you' to all my colleagues at work. It is a long time that I work on Dunant. I survived several moves, but we always settle back in and make 'home', over and over again. First of all, the other ladies from 'Le Jardin Bohemien': Diane, Lien, Caroline, Katrien, Kathleen, Meggie, Karen en Leen. I believe in our collective ways of living and working 'on the edge', very close to people that really matter to us. I really felt supported in the past period and this was heartwarming for me. I also have to thank all my other colleagues at the Department of Orthopedagogics. I will not name everyone of them, but a sincere 'thank you'. I miss the enjoyable moments with everyone together, more agora than silencio. We guide and cross the path of students in their becoming reflective practitioners. I cannot begin to name all the students I was very proud of, I hope they felt my appreciation. I just owe a very special 'thank you' to Hanne Vandebussche. Hanne, we shared stories on Deleuze and on Sofie. I still think with great pleasure on those precious moments.

I now want to return to the persons who are very close to me in my life. They know how 'hard' this was and how many times I had the feeling that I would not be able to pull it off...

A very big 'thank you', in a beautiful package with a red ribbon, to my parents, who are both very special to me. My father learned me to have respect for every living creature, persons, plants and animals. I accompanied him for hours and hours as a little girl, just sitting next to him while he was working. My mother was/is always there, my silent support and guidance. The hours she takes care of my children and looks out for my family, give me a very secure feeling. If I am dedicated to my work, I know where it comes from. I hope I can give my children the same nursing feeling as I felt and feel each time I arrive at home.

My family consisted of three more. I can say a very sincere 'thank you' to my sisters: Annelies, Catharina and Alexandra. My feeling to know what it means to be part of a family, only came because of you all. I slept for years together with my sister, Annelies, I know I can count on her (and

she on me) with my eyes closed. Catharina, I know this thesis is coming near for you too, I wish you lots of success, but I know you can do it. My little sister, Alexandra, who is not so little any more, I hope you can find your way and live your life with the same surrender and enthusiasm as I see you now working in the KSA.

I also cannot forget Hugo and Chris, the parents of Yannick. They always have a listening ear and are ready to help whenever necessary. The two of you also taught me that life can be hard and unfair, but you always get through it: together. With all my love, thank you.

Next to my family, I have my 'neighbours' and friends from the Brugse Poort. They mean very much to me and my family, because they are always there for us.

Katrien, I cried many tears in your company about my uncertainties. You stayed very calm next to me to give me advice and encourage me to go on. I know I can phone you or be in front of your door any moment of night and day. Thank you for being my wise friend.

Ariane, I don't know what I would have done without you these past months. I can never say 'thank you' enough for the company, the food, the taking care of my children, the translation... I do not know many people who would have done this, just as a warm gift of friendship. Thank you!

Koen and Didier are also two friends I want to thank for their support in the past months. Koen, I will never forget the weekend that you, Ariane and Yannick sat for two days in our living room to translate Dutch to English. I can only say: thank you. Didier, you phoned Yannick and me almost every day in these last months. I was always very pleased to receive a poem or an encouraging message from you.

A big 'thank you' to Eline Trelon. She helped me with last minute-translation and kind support.

Achiel and Jerom, my two little Indians. When we sit in the chair in the evening to read a book together and I see the two of you looking attentively with your big eyes, my heart is filled with pride. I enjoy the way the two of you are growing, each with his own personality. Becoming a mother made me decide never to judge on any mother/father any more. We can only do the best we can.

Yannick, where can I start? I know I am always glad to be able to tell my stories to your listening ear. I know I can ventilate at home and you not always agree with me. Thank you for being my 'compagnon de route'.. You are the personification of a rhizome, horizontal and with a thousand connections in your head and in your life. A multiplicity of interests and talents that make you the man I love with all my heart. If this work lies

here today, I know it is because we share some fundamental beliefs together, as soul mates. A very, very big hug!

A well-meant 'merci beaucoup' to all of you!

Elisabeth

Gent, 08 juni 2011.



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Chapter 1

General Introduction

Between the idea
And the reality
Between the motion
And the act
Falls the shadow

Between the conception
And the creation
Between the emotion
And the response
Falls the Shadow

Between the potency
and the existence
Between the essence
And the descent
Falls the Shadow

(T.S. Eliot, 1925)

1.1. Disability Studies

1.1.1. What's in a name?

"Disability Studies is an emerging interdisciplinary field of scholarship that critically examines issues related to the dynamic interplays between disability and various aspects of culture and society. Disability Studies unites critical inquiry and political advocacy by utilizing scholarly approaches from the humanities, humanistic/post humanistic social sciences and the arts. When specifically applied to educational issues, it promotes the importance of infusing analyses and interpretations of disability throughout all forms of educational research, teacher education, and graduate studies in education." (Gabel, 2005, p. 1).

Disability Studies is diverse and practitioners in the field engage in scholarly debate and discourse as social interpretists (Finkelstein, 2001; Snyder & Mitchel, 2001; Gabel, 2005) seeking to examine the lived experience and embodiment of disability. In this growing tradition, 'disability' is defined as a fundamentally social, cultural, political, historical and relational phenomenon (Barton, 1996; Davis 2002; Taylor, 2003; Devlieger, Pfeiffer, & Rusch, 2003; Danforth & Gabel, 2007). In contrast to clinical, medical or therapeutic perspectives on disability, Disability Studies focuses on how disability is defined and represented in society. From this perspective, disability is not a characteristic that exists in the person so defined, but a construct that finds its meaning in social and cultural context (Taylor, 2003). Gabel (2005, p. 4) uses 'social interpretation': "to refer to a wider array of disability theories in Disability Studies (e.g. disability identity, disability embodiment, disability discourse). As a whole, social interpretations of disability contrast with typical educational views wherein 'disability' represents innate individual deficits." Bérubé (1997, p. 2) points at the consequences of disability as a social representation: "Every representation of disability has the potential to shape the way 'disability' is understood in the

general culture, and some of those representations can in fact do extraordinarily powerful – or harmful – cultural and political work.”

Disability Studies is deeply entrenched in the social sciences and epistemology of the lived experience. Danforth and Gabel (2006) suggest that scholars look at the meaning of disability, how it is interpreted, enacted, and resisted in the social practices of individuals, groups, organizations, and cultures. Their perspectives served as a catalyst in research, trying to make sense of the lived experience of disability with the ultimate goal of emancipation and self fulfilment in all areas of life. Disability Studies does not emphasize barriers but embraces possibilities. Disability Studies covers an incredibly diverse group of people. Does it make sense to lump such different human beings under a simple category such as ‘disability’? It does – not because they are the same in any biological or philosophical sense, but because society has placed them in this category, with consequences for how they are viewed and treated by the majority presumed to be nondisabled. Disability Studies uses the perspectives and experiences of people with disabilities as the foundation for all research and training (Taylor, 2003). Each person has different, varied and valuable experiences and perspectives on his/her life. We always try to start from the capabilities of people and the kind of support people need to participate at home, at school and at work. We want to be aware of the label(s) that people drag along, and its impact on their activities.

“Disability Studies is not simply an academic paradigm. It is also an emancipatory paradigm: tied to the development of the disabled people’s movement (Campbell & Oliver, 1996), populated by a number of ‘organic intellectuals’ in Gramsci’s sense of the word (Oliver, 1990) and focused upon praxis – the dual promotion of social theory and social change (Lather, 1991)” (Goodley & Van Hove, 2005, p. 15). Emancipatory work presupposes cooperation with and is in the hands of people with disabilities. The experiential expertise of people has a lot of value that should be recognised and validated. This gives them a privileged position in relation to the professional/researcher. On both sides there is respect for each other and eye for equal dialogue and input. The person with a disability and the professional/researcher bear a shared

responsibility. We speak of a partnership with clear agreements, frustrations, tuning into positions...

“Disability Studies aims to:

- Work alongside and augment the politicization and expertise of disabled people
- Theorise and understand the conditions of disablement, exclusion, oppression and marginalization of disabled people
- Develop social theories of disability that expose the relational, material, cultural, political and social conditions of disablement
- Promote professional and lay practices that enable rather than disable
- Critique and inform disability legislation and policy that is anti-discriminatory
- Develop practices through which disabled people participate more fully in the process of research
- Encourage the individual and collective responsibility of non-disabled people to change conditions of disablement
- Build on and develop a social oppression model of disability
- Promote an inclusive community” (Goodley & Van Hove, 2005, p. 16)

1.1.2. Looking at ‘disability’ through different glasses

The understanding of disability as a social construction is not a unified, singular thing; there is no single model of disability, but rather a number of them, reflecting a variety of analyses and discourses (Smith, 2010). “Disability is not a ‘thing’ or condition people have, but instead a social negation serving powerful ideological commitments and political aims” (Connor, 2008, p. 447).

“A key strand is the problematizing of the ability-disability binary. (...) The instance of the normal-abnormal binary is central to the problematization of disability, particularly as it has morphed into the ability-disability binary central to the invention of categorical systems institutionalized by society (e.g. education, medicine, law, social policy).

How we 'other' the disabled body is determined by society" (Ware, 2001, p. 110).

"In Disability Studies, the disability-as-deficit notion is referred to as a clinical or medical model and is rejected as the basis for understanding the lived experiences of disabled people because it tends to pathologize difference and rely upon expert knowledge to remediate difference" (Gabel, 2005, p. 2). The medical model of disability is full of barriers and assumptions; it turns around curing, (preventive) treating, rehabilitating or segregating people with disabilities. Thinking in terms of 'restriction' or 'deficit' wants to deny, eliminate and compensate differences and mainly falls back on the knowledge of experts. While medicine and technology are part of the disability experience and can enhance life experiences for individuals with disabilities, the medical model as a theory is not about possibilities. The medical model is rooted in diagnosis (Schroeder, Gerry, Gertz, & Velazquez, 2002). "It asserts that labelled people have real and objective quantifiable deficits, located in their bodies and minds (rather than in physical or social environments). These deficits can be measured and understood, so this story of disability goes, through rigorous Cartesian taxonomies of difference, a process that might be described as a numbering of people. According to this model, these deficits and the people they inhabit can and should be fixed, eliminated or ameliorated through the use of instructional and other professionally controlled technologies. In essence, it posits that people with disabilities are broken, needing to be fixed" (Smith, 2010, p. 8).

The social model of disability as embraced by many scholars in Disability Studies understands disability as a form of oppression (Finkelstein, 1980). Oliver (1990, p. 32) believes: "It is not individual limitations, of whatever kind, which are the cause of the problem but society's failure to provide appropriate services and adequately ensure the needs of disabled people are fully taken into account in its social organization." Oliver suggests the social model places disability squarely in society. Indeed individuals with disabilities are oppressed and marginalized in society, but the experience of disability is more complex. By looking at disability only from a social perspective, the body and cognitive abilities are disregarded (Barnes, Oliver, & Barton, 2002). While much of the views and definitions of disability are socially constructed, the social model is not the answer to

that. Crow (1996, p. 66) pleads for a renewed social model of disability: "This model would operate on two levels: a more complete understanding of disability and impairment as social concepts; and a recognition of an individual's experiences of their body over time and in variable circumstances. This social model of disability is thus a means to encapsulating the total experience of both disability and impairment. (...). An impairment such as pain or chronic illness may curtail an individual's activities so much that the restriction of the outside world becomes irrelevant and that... for many disabled people personal struggles relating to impairment will remain even when disabling barriers no longer exist." A strong social model tends to have a fairy tale type belief that when social constructs are broken down, individuals with disabilities will be able to independently access their world. Individuals with significant intellectual and physical disabilities are still excluded. On the other hand, it is not possible to ignore the social aspects of disability.

The experience of disability has to do with voices AND silences, oppression AND power, medical supports, labels AND societal expectations. Resistance theory exposes and embraces the story of the disability in its entirety. Resistance theory goes beyond strict social theory and is all about possibility. According to Gabel (2005, p. 8): "A resistance theory of disability maintains the social model's focus on the politics of disablement and adds to it recognition of the complexities of resistance." Resistance theory looks at the whole picture, the entire experience, not one side or the other but the entire experience of disability. Gabel and Peters (2004, p. 588) understand disability as a "quintessential post-modern concept, because it is so complex, so variable, so contingent and so situated. It sits at the intersection of biology and society and of agency and structure. Disability cannot be reduced to a singular identity: it is a multiplicity, a plurality."

1.1.3. Disability Studies at Ghent University

What are typical elements of Disability Studies that are very central in research, teaching and action? According to Van Hove (2010), we can fall back on:

- *Participation* is essential.

Everything revolves around participation. It is not enough to be present, participation is something more: it is about belonging and be actively involved in whatever is going on (Biklen, 1992). Disability Studies makes us listen very carefully to what people want and how they want to participate in it. It makes us think about ways we can/should support people to enhance their participation and opportunities to participate. In 1994, on the World Conference on Special Needs in Education, the Salamanca Statement (p. 11) said: "Inclusion and participation are essential to human dignity and to the enjoyment and exercise of strategies that seek to bring about a genuine equalization of opportunity." In addition, we are interested in the barriers which people face and which prevent them to participate.

- Disability Studies turns around *talents, dreams and desires* of people with a label.

We have years focused on what people are not good at, on what people are not allowed,... Professionals sometimes behave like managerial 'ticking boxes' (Parton & O'Byrne, 2000). It is a challenge not to fall into that trap. We want to explore explicitly talents, dreams, desires and plans. This is about handling many questions that need negotiations with other people closely involved. How can we understand who the child and his/her potentiality actually is? How can we support this child and his/her parents on their journey?

- We write us with Disability Studies into a *human rights discourse*.

The UN Convention on the rights of people with disabilities ratified by Belgium in 2009 is an important guide for the way we support and encourage people to go. We are not in the position to talk about what is 'relevant' to a 'group' or 'category'. We are not in the position to say

what is 'reachable'. Barton (1997, p. 234): "Inclusive education is part of a human rights approach to social relations and conditions. The intentions and values involved relate to a vision of the whole society of which education is a part. Issues of social justice, equity and choice are central to the demands for inclusive education. (...) Inclusive education is concerned with the well-being of all pupils, and schools should be welcoming institutions."

- People with disabilities have their *own voice*, their *own story* and that must come first.

"A crucial feature of the oppression of the disabled people has been the extent to which their voice has been excluded. Overcoming disabling barriers will include listening to the voice of disabled people and their organizations, especially as they struggle for choice, rights and participation" (Barton, 1995, p 159). The voices of family members (of other people who are very close) cannot be regarded as a substitute for the voices of people with disabilities themselves. The person with disabilities always comes 'first', is listened to, is offered opportunities for communication and is not ejected with classics such as 'searching for attention' or 'not knowing'.

- Disability Studies believes that *families, natural networks and the ordinary places and actions in society* come first.

Disability Studies recognizes the important role that family members play in the lives of many persons with disabilities. Scholarship in this area includes research into the views and experiences of family members of people with disabilities. Embedding the individual in a web of relationships ensures greater opportunity for shared identity formation with multiple social partners (Ferguson, 2003). Murray and Penman (1996, p. vii) make very clear how they think about segregated and specialized systems: "For us the concept of segregation is completely unjustifiable – it is morally offensive – it contradicts any notion of civil liberties and human rights. Whoever it is done to, wherever it appears, the discrimination is damaging for our children, for our families and for our communities. We do not want our children to be sent to segregated schools and any other form of segregated provision. We do not want our children and families to be damaged in this way. Our communities should not be impoverished by the loss of our children."

- Disability Studies is based on the assumption that *people with a professional role must recognize their subjectivity* and give it a place in their relationship with others.

We do not believe in "professional detachment". People have to take each others' expertise seriously. To us 'modest relations' (Goodley & Van Hove, 2005; Van Hove, Roets, Mortier, De Schauwer, Leroy, & Broekaert, 2008) are the central motive. Disability in a pedagogical context becomes a relational concept. Assumptions about 'normality' and the reproduction of structural differences are disclosed and mirrored in these modest relationships. In view of this choice, we cannot stay (in research and practice) neutral in a Freirean perspective; this leads to communal activism and resistance in order to further a longed-for social change (Freire, 2004). "It is a living engagement. It applies to resources of our creative imagination in an attempt which is as much to disclose something about ourselves as it is to disclose something about them. It is an engagement that tries to find a way of being open to them and a way of learning from them and which, having tried once, will return and try again, renewing, renewing, renewing" (Campbell, 1995, p. 237). In this way our pedagogical work becomes a combination of a political act, a creative act and an act of knowing (Gadotti, 1998, p. 2).

- Disability Studies believes very strongly in the strengths of a '*reflexive practitioner*'.

"Critically reflective practice according to this model is an approach to practice that involves (i) asking searching questions to get beneath the surface of the situations we encounter to ensure that we have more than a superficial grasp (Murray and Kujundzic, 2005); and (ii) takes account of wider social and political processes that disadvantage marginalised groups of people and reinforce patterns of discrimination and oppression (Mullaly, 2002)" (Thompson, 2008, p. 3). He/she who is querying constructively-critical situations and organizations; not just simply querying, but to get started on a way to a better world for all citizens.

- Disability Studies is not afraid of '*contradictions*'.

"Dilemmas are revealed as fundamentally born out of a culture which produces more than one possible ideal world,... social beings are confronted by and deal with dilemmatic situations as a condition of their humanity" (Billig et al, 1988, p. 163). It must be possible to think about

and search for various 'entrances' within the same problem/challenge. Pedagogues are not like plumbers, who immediately need to solve the problem. Complexity is the norm and we have to take different options into account.

- Disability Studies is interested in phenomena like 'disability' from a *historical and comparative attitude*.

How were phenomena that we now know in the past? How are phenomena that we tackle in other cultures? From such analyses, much can be learned. The field of (special) education is full of histories that define and classify individuals according to specific concepts and along specific lines. These not only mark the individual development of those who are subjected to these procedures but also open up the possibilities for them to become agents of their own realities.

- Disability Studies goes hand in hand with *action*.

We cannot be bystanders with our hands in our pockets and wait... We have to act together with people with a disability and their families.

1.2. Inclusion and inclusive education

1.2.1. Inclusion

Inclusion is hard to define, the focus should not be on what inclusion means, but rather on the meanings of inclusion. They need to be understood in their diversity (Barton & Armstrong, 2001; Nind, 2005; Cole, 2005). "In spite of the fact that there is no clear consensus on the meaning of inclusion, there is a diverse body of research about inclusion – about what it does- that has been explored over a long period of time" (Smith, 2010, p. 39).

Inclusion is a difficult and multifaceted process. There are no easy answers, no packaged solutions to inclusion, that can be daunting. Inclusion has to be interpreted in different ways in different contexts.

Putting different meanings of inclusion in a row is not easy. We do not put them in matter of importance. Some of the meanings overlap each other. We do not try to be complete. Inclusion is not or... or, but and... and: one meaning does not eliminate another. We have the intention to show that the flag of 'inclusion' covers a lot of cargo. We try to unravel some of the meanings.

Inclusion is about the right to belong in society.

Lutfyia (1995) talks about membership: inclusion is about real membership. All members want to form a community, a community that is the foundation for further relations and more participation. Bayliss (1995 in Van Hove, 1999, p. 16) sees inclusion literally as belonging: inclusion is a fundamental right that has to do with belonging and connectedness. Including students with (substantial) disabilities in regular classrooms heightens awareness of each interrelated aspect of the school's life as a community: its boundaries, its benefits to members, its internal relationships, its relationships with its outside environment, and its history (Taylor, 1992). Halvorsen and Neary (2001, p. 3) also put emphasis on membership, when defining inclusive education. Students who happen to have disabilities are seen first as kids who are a natural part of the school and the age-appropriate general education classroom they attend. It is important to building a sense of community in inclusive schools in which all students are valued members and an educational program that addresses the needs of students across cultural, language and ability differences (Ferguson, Kozleski & Smith, 2003; Hunt, Hirose-Latae, Doering, Karasoff & Goetz, 2000). Allan (2005, p. 282) writes: "Inclusion starts with the premise that an individual has a right to belong to society and its institutions, which therefore implies that others have obligations to ensure that this happens. Inclusion necessitates the removal of barriers that may prevent individuals from belonging. These barriers may deny individuals access to buildings or material or cultural resources, or may convey messages to individuals according to which they do not really belong. Removing those barriers implies structural and attitudinal changes and a fundamental shift from the deficit-oriented thinking that has for so long driven educational practices."

Inclusion focuses on capabilities.

Reindal (2009, 2010) starts from Nussbaum's capability approach. "It makes it possible to rethink inclusion within a frame of human flourishing whereby the development of capabilities is at the core of inclusive education. The capability approach gives us an understanding of difference that is both individual and relational. Adapting the view of difference as a specific variable within the social-relational model of disability provides the opportunity to discuss the additional needs without sliding into individual models". Terzi (2005, p. 443) explains: "The capability approach as a framework for assessing inequality, proposes that equality/inequality be judged in terms of capabilities, rather than other factors, such as income, welfare, etc. Capabilities refer to real freedoms. A focus on capabilities requires an analysis of the interaction between individuals and their social circumstances." Terzi uses this assumption to argue against the false opposition between individual and social causes of disability, what are often called the medical versus the social model. In distinguishing between impairments (loss or lack of function) and disabilities (inability to perform some activity) she shows that disabilities are in relation to both impairment and the design of social arrangements. So, the capability approach focuses on what people can do or be and their potentialities. As Terzi points out, one of the benefits of the capability approach is that judgements about equality/inequality become a matter of capabilities, not about the causal origins of their disabilities. What matters is not the causes of the disabilities but that disabilities are limitations on relevant capabilities.

Inclusion is about equity and quality for all children.

Inclusion is not a disability issue. Inclusion is an educational equity and quality issue for all students (Giangreco, 1997, p. 194). Kunc , Pearpoint and Forest and Bayliss talk about the valuing of difference(s):

- The fundamental principle of inclusive education is the valuing of diversity within the human community (Kunc, in Bayliss, 1996, p. 29-40).

- An inclusive school cherishes and honours all kinds of diversity as an opportunity for learning about what makes us happy (Pearpoint & Forest, 1992, p. xvi)
- Inclusion and inclusive education is a process that starts with the valuing diversity in a community: all citizens are able to contribute (Bayliss, 1995 in Van Hove, 1999, p. 16).

Pijl, Meyer and Hegarty (1997) describe that inclusion starts with the differences among children and these should be the starting point in educational and support services. For Gewirtz (1998) relational justice is linked to 'justice as recognition' which is about the recognition of differences between groups and individuals in terms of various identities. In arguing for the importance of both aspects of justice, Gewirtz notes that the distributional aspect is individualistic in its focus on what individuals are due, while the relational aspect is more holistic and social with its focus on the interconnections between individuals and groups; it is about solidarity.

Inclusion AND exclusion.

The mechanisms of 'differentiation', 'categorization' and 'spatialization' of individuals are the products of the norm. "A norm, or rule is what can be used to right, to square, to straighten. To set a norm (normer), to normalize, is to impose a requirement on an existence, a given whose variety, disparity – with regard to the requirement- present themselves as a hostile indeterminacy" (Canguilhem, 1989 as cited in Snyder & Mitchel, 2001, p. 373). Gallagher (2010) makes clear what are the consequences from this norm in society: "The concept of normal has had a decidedly coercive effect on people. If to be normal is to be all right, one is prompted, urged almost instinctively to aspire to the normal state, to conform to ideals of what is normal received from experts and internalized in the everyday consciousness. Subsequently, to be abnormal was to be avoided at all costs." Graham and Slee (2008) see that a person can be put 'in' or 'out' through that disciplinary power. They ask themselves: What can we do to disrupt those mechanisms? What can we do to threaten the balance of the centre and create confusion about who is 'in' and 'out'? The privileged notion of 'the permissible and the normal' (Macherey, 1992, p. 177) can only exist when related with the negative,

pathological minority, the Other. "We can start to conceptualise how it is that education, as a field of application of normalizing judgement, both sets up and is beset by the conjoined nature of exclusion/inclusion" (Graham & Slee, 2008, p. 88). Naming or labelling works not only to differentiate but also to defer. It brings certain features to the front and make differences visible, while it also covers up, naturalizes and makes other characteristics invisible. Playing with that (in)visible difference works "to maintain power imbalances and structural inequity by reifying unnamed attributes that carry social, political and cultural currency" (Graham & Slee, 2008, p. 93). We must also acknowledge and ameliorate the gaps arising from our efforts to include.

Inclusion is about striving for social change.

Barton (1995) thinks it is essential that we do not underestimate the serious, complex and contentious nature of the issues involved in the pursuit of inclusive policies and practice. The process will be challenging and disturbing, necessitating fundamental changes to the social and economic conditions and relations in a given society. This will include changes to the values informing the prioritization and distribution of resources, how society views difference, how schools are organized, how teachers view their work, the styles of their teaching and the nature of the curriculum. The dilemma of difference is not an accidental problem in this society. "The dilemma of difference grows from the ways in which this society assigns individuals to categories and, on that basis, determines whom to exclude from political, social and economic activities" (Minow, 1990, p. 21). Inclusive education implies a change in mentality. It means that the view of the world, and thus on people changes. Every child is part of society, just because it is who it is (De Vroey & Mortier, 2002). Barton and Armstrong (p 708) see inclusive education not as an end in itself but a means to an end- that of the realization of an inclusive society. This necessitates schools adopting a critical stance both internally and externally toward all forms of injustice and discrimination.

1.2.2. Inclusive education

We try to be clear about what we talk in this thesis when we refer to 'inclusive education'. The definition of Giangreco (2006, p 4) is still very coherent with a lot of different aspects of inclusive education framed:

"All students are welcomed in general education. The general education class in the school the student would attend if not disabled is the first placement option considered. Appropriate supports, regardless of disability type or severity, are available.

Students are educated in classes where the number of those with and without disabilities is proportional to the local population (e.g. 10-12 % have identified disabilities).

Students are educated with peers in the same age groupings available to those without disability labels.

Students with varying characteristics and abilities (e.g. those with and without disability labels) participate in shared educational experiences while pursuing individually appropriate learning outcomes with necessary supports and accommodations.

Shared educational experiences take place in settings predominantly frequented by people without disabilities (e.g. general education classes, community work sites, community recreational facilities).

Educational experiences are designed to enhance individually determined valued life outcomes for students and therefore seek an individualized balance between the academic-functional and social-personal aspects of schooling.

Inclusive education exists when each of the previously listed characteristics occurs on an ongoing, daily basis."

Giangreco's definition is a powerful one because: it speaks about all students, not just those with disabilities; it describes special education as

a process, not as a place; it speaks to the rights of students; it describes students, both with and without disabilities, as being a shared responsibility for all schools and educators; and finally, it describes school as a place of community; and as a place which to create community (Smith, 2010, p. 43).

Inclusive education needs to be part of a whole-school equal opportunities policy. Barton (1995, p. 160) writes: "It is essential that the demand for inclusive education does not result in a critique of special schooling which becomes an end in itself. We are not advocating that these developments are merely in terms of the existing conditions and relations in mainstream schools. They too will need to change and there are certain features that are unacceptable, including the plant, organization, ethos, pedagogy and curriculum. It will demand the transfer of resources, careful planning and continual monitoring. We are not advocating a dumping practice into existing provision."

Reindal (2010, p. 10) understands that inclusion has to be seen in relation to the core mission of education: "As Hegarty (2001) pointed out, parents send their children to school to be educated, not to be included. Inclusion is something one expects from the school's practices so that their children will be treated fairly, protected from harm, and taken care of as well as not being excluded and isolated from classmates."

What we said about inclusion, also plays in the use of 'inclusive education'. Inclusive education shows itself in a lot of different fragments, according to time and place. It is a complex set of factors that interact. Through the various stories of children and young people in inclusive education, we can see elements that reoccur and influence the process in a positive/negative way. We can make those elements visible by looking from different angles to 'inclusive education': what do children, teachers, peers, parents, support workers... have to say about it?

1.3. Contextual framework in Flanders

In Flanders we have a two-track system in the education of children with a disability. We have a very strong and intensively built special education and a limited range of possibilities in the regular education system. We do not seem to be able to find a consensus around the recognition of inclusive education in our educational legislation. We can hardly find the word 'inclusion' or 'inclusive education' in our educational policy: it is an 'infected' word that mobilizes a lot of resistance.

Special education

There is a growing number of children receiving special education (7 % à 8 %). About one pupil in 10 is not anymore in the regular school circuit at the time of the switch to the secondary school (Mardulier, T., personal communication, 6 may 2011). About 70% of these pupils get education in a special school, type 1 (mild intellectual disability) and type 8 (learning disabilities). Children from disadvantaged background and immigrant children are over-represented in special education.

Integrated education (GOn)

We have a system of integrated education that allows disabled children to go to a regular school, on condition that they live up to the existing standards. The school receives support from special education teachers who mainly work on an individual basis with children. It is about stimulating collaboration between the regular and special education. Integrated education focuses on "young people with disabilities and/or learning and parenting difficulties temporarily or permanently, who are partially or fully able to follow the lessons or activities in school with help from a school for special education" (Vandevælde, Mortier & Van Hove, 2006, p. 155). Concrete, pupils receive 2 hours (max. 4 hours) of support in one week from a special educator.

Inclusive education (IO_n)

Currently, the only way to receive support for children with ‘moderate or severe intellectual disabilities’ (type 2) is through a special government project that aims at including 100 children in regular education, with the support of special educators. “These children and young people in primary and secondary education are not expected to reach the same learning objectives and curriculum standards. They can develop their individual learning trajectory. The emphasis is therefore on the social integration in the classroom” (Flemish Agency for Persons with Disabilities, 2011). The students and their teachers get support from a special educator (type 2) for 5.5 hours a week.

This does not mean that these children are the only children in inclusive education (Van Hove, Mortier, & De Schauwer, 2005). There are a lot of ‘partisans’. A lot of children, parents and schools are doing inclusive education but do not fit in one of these systems described above. They are not awaiting new laws and legislation. They combine (a lot of) different support systems in order to get extra support into the classroom: integrated education/inclusive education support, direct budget, volunteers and students, therapists, etc. There is a very active movement of parents who make different choices for their disabled children than the integration or segregation opportunities they get. The query about inclusive education comes from families who want their child to go to a mainstream school in the neighbourhood, along with their sibling(s) (Mortier, De Schauwer, Vandeputte & Van Hove, 2010).

1.4. Outline of thesis

However simple something seems, it will appear different if you approach it from a different angle. When we consider the development of inclusive education and practices, we need to remind ourselves that our communities are made up of billions of versions of the simple and obvious. Beneath each layer of understanding, however much it may seem to be common sense, are layers of socio-cultural and personal complexity. Inclusive education is, in our view, an attempt to make sure

that generalizations are constantly tempered by questions; it is a call for us to step back from our certainties and listen to other perspectives. We are not looking for 'consensus' and 'truth', we want to put the light on several perspectives and scrolling to complexity and coherence.

In Chapter Two we look at the perspectives of children and their experience with inclusive education. The aim is to highlight how children talk about their capacities, difficulties and schooling.

In Chapter Three we go deeper into the perspectives of the parents. With the use of metaphors, we see how parents are living together with their child with a disability and struggling for inclusive education.

Chapter Four discusses the perspective of teachers. Through the 17 stories of the teachers, we come to reoccurring patterns and themes that give us insight in the position of the teacher towards inclusive education. All of the teachers had experience with a child with significant challenges in their classroom. We are going into the very concrete question: "How did inclusive education work in your class?"

Chapter Five focuses on Sofie and her participation through primary education. The aims of such qualitative research seek to generate both descriptive and procedural knowledge that can lead to greater understanding of individuals with disabilities, their families and those who work with them (Brantlinger et al., 2005). The six years I worked with Sofie as a personal assistant were brought together through information from personal notes, diaries going from home to school, interviews, observations...

Chapter Six looks at my own position throughout this process. It looks at some of my becomings as a personal assistant, a coach of teams around a child in inclusive education and as researcher.

The final chapter attempts to make sense of what are central concepts throughout this thesis. We fall back on five concepts and go into this in a more profound way.

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Chapter 2

**“I need help on Mondays, it’s not my day.
The other days, I’m ok.”
Perspectives of children with a disability
on inclusive education.¹**

¹ Based on De Schauwer, E., Van Hove, G., Mortier, K., & Loots, G. (2009). I need help on Mondays, it’s not my day. The other days, I’m ok.” Perspectives of children with a disability on inclusive education. *Children and Society*, 23(2), 99-111

"I can't believe THAT!" said Alice.

Can't you?" said the Queen in a pitying tone. "Try again: draw a long breath, and shut your eyes."

Alice laughed. "There's no use trying," she said, "one can't believe impossible things."

"I dare say you haven't had much practice," said the Queen. "When I was your age, I always did it for half-an-hour a day. That's why sometimes I believed as many as six impossible things before breakfast!"

(Alice's Adventures in Wonderland, Lewis Carroll, 1865)

Abstract

This article examines the experience of inclusive education from the perspective of children with a disability. We worked with the observations of and interviews with 15 children, aged 5 to 17 who go to a mainstream school. The study is set in the context of a three-year research project exploring the practice of inclusive education in Flanders. Here, we report on the key findings from the children's accounts, focusing on what they had to say about themselves, what they think about school, friends, support and their future prospects.

2.1. Introduction

This paper is the result of a research project subsidised by the Flemish government (Department of Equal Opportunities) between 2002 and 2005. The goal of the project was to identify critical factors underlying 'good practices' of inclusion. We explored the daily experiences of how inclusive education can work for a child in the classroom from the perspective of several stakeholders. This study, called 'Inclusive education in the Flemish Community', involved 30 children between the ages of 3 and 18. The research was conducted in a qualitative way with observations, interviews and information analysis inside the children's school, home and leisure environments. A full account of the study in Flemish can be found in Van Hove, Mortier and De Schauwer (2005).

We held in-depth interviews with 15 of the children. The purpose of this study was to find out the experiences of the disabled students themselves. In order to take the position of each person involved in the process of inclusive education seriously, we wanted to pay special attention to the view of the disabled child. Background literature revealed: "The views of ill and disabled pupils themselves constitute a particular gap in existing knowledge. Despite a growing awareness of the importance of engaging directly with children in research rather than using adult 'proxies', disabled children remain a neglected group" (Lightfoot, Wright, & Sloper, 1999, p. 268). This is also confirmed by Allan, 1999; Davis, Watson and Cunningham-Burley, 2000; Mitchell and Sloper, 2001; Barker and Weller, 2003; Norwich and Kelly, 2004; Curtin and Clarke, 2005 and Broer, Doyle and Giangreco, 2005. Through this research project, we intended to put in concrete terms and to describe the perspectives of children on inclusive education. We did not want to make any judgements on what was positive/negative or true/not true in their situation.

2.2. Literature review

We went through literature that focuses on children's perspectives. Some of the key themes will be discussed in the following paragraphs.

When young people are looking at their disability, it is only one aspect of life. They put a lot of different meanings on it:

"Being disabled meant that they encountered disabling barriers in the social world (mainly access and attitudes). For other children, being 'disabled' meant having a visible physical, sensory or cognitive impairment. This definition of disability meant that some children with a hidden impairment could exclude themselves from the category. Some children gave a very specific and practical explanations of disability in terms of the way impairment impinged on their lives." (Watson et al., 2000, p.19)

In research of Connors and Stalker (2007), children talk about impairment in using the word 'disability'. They are able to put in concrete terms the consequences on their daily life:

"The children did tell us about what Thomas (1999) called 'impairment effects' (restrictions of activity which result from living with impairment, as opposed to restrictions caused by social or material barriers). At the same time, most seemed to have learned to manage, or at least put up with, these things. Most children appeared to have a practical, pragmatic attitude to their impairment." (Connors & Stalker, 2007, p. 24)

Parents play an important role as mediators towards the school, by giving information and resolving problems when teachers/pupils don't understand their child's needs. (Lightfoot, Wright, & Sloper, 1999).

The attitude of staff at mainstream schools is crucial in the experiences of the pupils. Lightfoot, Wright and Sloper (1999) see that children know the teachers who are aware of their difficulties. They appreciate teachers who try to understand them. When adults slow down the pace or are flexible in learning arrangements, pupils are very grateful. These findings are shared by Lovitt, Plavins and Cushing (1999) and Curtin and Clarke (2005).

Teachers and staff at school are important actors in the positive ethos of the school towards disabled children. Davis and Watson (2001, p. 680)

refer to those adults as reflexive practitioners: "Their comments reinforce the belief that children, whatever the level of their impairment, should be treated as competent social actors who can be included in the everyday processes of schools if the necessary structural, cultural and individual issues are addressed."

Allan (1999, p. 116) assigns teachers a significant role in helping to build the identity of their pupils: "Teachers might help pupils to explore their sense of self – expressed as desires rather than needs- and to analyse the constraining and enabling factors, but should avoid passing judgements on them."

On the other hand, Watson et al. (2000) state the risk of surveillance coming from adults. Children with a disability in schools are under closer surveillance than non-disabled children. The extra support coming from adults have sometimes the effect of control and make children feel excluded from their peer group.

In almost all of the research, friendship is a topic that young people talk about. It is clear that disabled and non-disabled children can form friendships (Lightfoot, Wright, & Sloper, 1999; Norwich & Kelly, 2004 and Curtin & Clarke, 2005).

Yet, there are some considerations that go together with this. Such friendships do not automatically follow from a mainstream school environment.

"Attending a mainstream school does not automatically lead to young people with and without disabilities mixing. Some people with disabilities may be more comfortable mixing with pupils with whom they feel they have more in common, appreciating the peer support and sense of belonging that Mulderij (1997) and Widdows (1997) consider essential for developing social skills and a healthy self-esteem." (Curtin & Clarke, 2005, p. 210)

Support is always part of the friendships that do arise. However, it can sometimes dominate the relationship and then we can question the meaningfulness. When relations are dominated by the assumption of need and care, the peers behave not as equals, but more as guides or helpers. (Watson et al., 2000) This is also an important issue for students in secondary school, according to Lovitt, Plavins and Cushing (1999).

2.3. Method

For the Inclusive education in the Flemish Community project, we selected a group of 30 children with a disability. We gathered them by using our own practice in coaching educational teams and supplying Master students (in special education) as support workers in the classroom. We also worked together with the parents' organisation 'Parents For Inclusion' and with professional organisations working with parents of children with a disability. This provided us with a group of 30 children with a wide range of characteristics with regards to age, gender, disability, support needs, location and type of school. All these children had the chance to participate. We sent their parents a letter asking for their permission to work with their child. Lewis (2002) refers to parents as gatekeepers, either providing or withholding access to the children to be interviewed. Children and young people themselves were asked whether or not they wanted to be involved and if the interview could be recorded. Their right to withdraw at any moment was explained in clear terms to them and their parents (Davis, 1998). From the 30 young people, 15 wanted to co-operate. We received a lot of different reasons why the children did not respond: the children did not want to participate, parents did not give their permission, it was not convenient at the time, the child was in hospital, parents thought their child's means of communication was too complex or that their child was too young.

We worked with five interviewers, all of whom were professionally involved in the area of inclusive education. We matched the interviewer with situations she already knew. This way of working enabled an informal style to be developed and a wide-ranging exploration of ideas. The interviewers made observations in the classroom and at home and monitored the child's engagement during the interviews.

Semi-structured interviews and observations, lasting between 1 and 1½ hours maximum, were carried out with each disabled child at school and in their own homes. A common interview framework was drawn up among the different interviewers to cover various aspects of the children's perspectives. Specific questions were tailored to the particular circumstances or characteristics of each child.

- How do the children and young people regard themselves?
- Who are the important people in their lives?
- What do the children and young people do at school? How do they feel about school?
- What are their future prospects?

In most cases, the children were visited twice at school and once at home. There was also a conversation with the parents to discuss the data resulting from communication with the child at a younger age (<7). In some cases, communication was not so intensive because of practical circumstances: the child was sick, the car broke down, there was too much going on at school, etc.

All respondents were told that their replies were anonymous, and that their names would be changed. This seemed to be particularly important for the older pupils.

The design of our research required the use of more creative methods of communication for children who do not communicate verbally (Morris, 2003). Researchers were engaged to do this because they had already known the children for a longer period. They worked by interpreting the children's body language, as well as using tools for augmentative communication. The mother of the child, the support worker and/or a speech therapist helped to interpret responses that were not clear.

The following table provides background information about the 15 participants in this study. All of them follow education in a mainstream school setting. There are no special units in the regular school. Three of the 15 children (marked with *) have previous experiences in special education.

Name	Age	Gender	Label	Class	Support	Communication Support
Yentl	11	girl	intellectual disability	primary school (5 th)	volunteers	no
Liz	13	girl	cerebral palsy	secondary school (1 st)	special educator + volunteers	no
Nathalie *	17	girl	intellectual disability	secondary school (4 th)	Direct budget + volunteers	no
Jeffry	5	boy	intellectual disability + ADHD	kindergarten (2 nd)	volunteers	mother
Emma *	11	girl	cerebral palsy	primary school (4 th)	direct budget	speech therapist, augmentative communication device
Arash	5	boy	syndrome of Noonan	kindergarten (3 th)	volunteers	no
Sara *	11	girl	cerebral palsy	primary school (4 th)	direct budget + special educator	speech therapist, augmentative communication device
Thomas	10	boy	Down Syndrome	primary school (3 th)	special educator + volunteers	no
Nizreen	14	girl	cerebral palsy	secondary school (2 nd)	direct budget	no
Yasmine	6	girl	intellectual disability	kindergarten(3 th)	volunteers	no
Martha	8	girl	cerebral palsy	primary school (2 nd)	special educator + volunteers	no
William	5	boy	motor problems	kindergarten(3 th)	volunteers	no
Kathy	10	girl	motor problems	primary school (4 th)	direct budget	no
Julie	5	girl	cerebral palsy	kindergarten (3 th)	volunteers	speech therapist, augmentative communication device
Lisa	16	girl	Down Syndrome	secondary school (2 nd)	special educator + volunteers	no

2.4. Analysis

With the permission of the children and parents, observations and interviews were transcribed in full. All of the material was shown to the children and their families, so that they could decide whether it could be used or not. Each manuscript was carefully read through several times and was subjected to a content analysis. For this analysis we followed the inductive and conceptual mapping procedures as suggested by Clarke (2005) and Charmaz (2006). Reoccurring themes, common patterns and key points were identified by the first author after coding the interviews (Patton, 1990; Bogdan & Biklen, 1998). The themes were examined for consistent patterns and exceptions. Within the group of interviewers the inter-relationship between the most important variables were discussed. Searches for a possible causality between variables of a higher and lower level of abstraction were made within the group of authors.

We are fully aware that the participants in this study are not representative of all young people in inclusive education with a disability. Nevertheless, this research project gives us some valuable insights into how children/young people are involved in their own education process.

2.5. Findings

We have included a lot of quotes from children in this paper as a way of giving them a voice.

Just another kid

"I like to play with Play-mobil. I collect bears and books. I like to draw. I can tell you everything about Spy Kids, Lord of the Rings and Harry Potter. I have my own mail address. During holidays I don't want to get up early, I like to be lazy then." (Yentl, 11)

Children with a disability are just regular persons with everyday interests, desires, activities, worries, choices... Ordinary things determine their lives, not just the difficulties or disabilities they have. Their worlds and ways of living show a lot of similarities with their peers. They are very active children with a lot of activities.

"Once a week, I go dancing in my wheelchair. My friend Ann from school joins me. I also ride horses. I wouldn't be able to live without it." (Liz, 13)

The children give us a lot of material about their hobbies outside of school, as they invest a lot of time and energy in this. They spend a lot of time in mixed groups of disabled and non-disabled children.

Capacities and abilities

"I am good at cooking. This morning I have baked pancakes, but some of them went wrong. I can do the washing up and the drying. At school I am good at physical education. I like to co-operate in the classroom." (Nathalie, 17)

Children spend a lot of time talking about things which they think they are good at. This is not always related to their intellectual abilities. Their interests and talents can become points of contact in their learning process and can help to make choices, add content to subjects at school, give direction to their field of study and leisure time.

Jeffry (5) has a long list of all the things he likes to do: paint, stamp, draw with crayons, cut with his scissors and work with clay. The teacher says that Jeffry likes to paint in his way but he cannot work on paper and colour something in. He can cut if you take his hand. If you don't watch him, he cuts the head or a leg off. His fine motor abilities are not good."

Being active and doing the things you like to do is more important than being able to master things. In a lot of interviews and observations, the children give us information about what they like and do not like to do. They talk more in these terms than about the things they are able to do or not. Grown-ups in their environment can think differently about this.

Impairments and difficulties

"I react differently, sometimes. I am slower. I need help sometimes. I don't understand everything. Everybody has brains. Me too, but they work a little bit slower." (Nathalie, 17)

The respondents make it clear to us that they are aware of being different. Their difficulties are part of who they are. Some children are very explicit about this. They talk about their motor problems. Older children describe better what is difficult for them.

Yentl (11) talks about her difficulties with maths. "I have to use my cards to know my multiplication tables."

When pupils talk about their disabilities, they talk a lot about the way they handle their difficulties. Some young people relate this to bad performances in some school subjects.

The teacher asks everyone what his/her favourite colour is. The assistant takes the communication book. She searches for the right page with all the colours. It takes a while before Emma can make her choice clear. She has to pick a colour and a number to discover the right position in the block. In the meantime, the teacher continues: "We will give Emma some more time, give a sign if you are ready." (observation Emma, 11)

There are moments when children are confronted more explicitly with their difficulties. These problems have to do with communication, pace, the teacher being very busy, the child having a difficult day, the kind of activity, etc. The children themselves recognise that they are different but, as they make clear, this difference only becomes relevant at certain times and in particular contexts.

Belonging

Belonging is a basic need for each person (Kunc, 2002). Membership refers to a child's right to have access to the same opportunities and experiences as non-disabled peers. Children with a disability start from what they have in common with peers and show in lots of different ways that they can and want to belong. They want to contribute and be part of the class and school context. Students' sense of belonging, self-esteem and engagement are all affected by participating in the regular activities of the classroom alongside their peers (Williams & Downing, 1998).

Nathalie signs her letters and drawings with: Nathalie Spriet, 2BKVV. [name of her class] (observation Nathalie, 17)

Children and young people are looking for linkages with their peers. This becomes clear in our conversations and observations.

The exercises you don't finish in class, you have to take home. Because I don't write very well, I have more homework. That is not fun! When I was in primary school I didn't have homework when I had to go to therapy. In secondary school, they cannot take this into account. If I work more during the weekends, I can handle this. (Liz, 13)

Young people with a disability sometimes have to prove themselves when they want to take part in the educational process. Pupils can and have to work very hard. They show that they have a lot of abilities but nevertheless it requires a lot of energy.

About school

"On Monday we can paint, Tuesday, we ride our bicycles, on Wednesday, it is only half a day, on Thursday I work with Anne (speech therapist) and on Friday we make bread." (Arash, 5)

Children like to go to school. They tell a lot about their subjects, class and school.

Sara (11) showed pictures of Celine, Aurelie and Nathalie during her interview, she calls them 'friends'. She knows the name of her teacher 'Marleen' and her physical therapist 'Inge'.

The children talk a lot about who they meet in school, about classmates and teachers.

Jeffry (5) likes school outings, school treats, birthdays and Santa Claus.

Most of the time, the stories about school are about non-academic activities. Children put a lot of emphasis on the community aspect. They talk about field trips, school treats, what happens at the playground, etc.

"I cannot put my shoes on my table. The teacher doesn't like it." (Thomas, 10)

Children learn what is necessary to maintain their position in class. They have specific goals in this area where, for non-disabled children, this is often expected without questioning. Children with a disability experience the way things work in a mainstream environment; they learn the rules and habits of the teacher and the classroom. They give us a lot of information about this in their interviews.

"The teachers know and accept how I am and how I work. I wouldn't like to start all over again." She talks about her class teacher in a negative way. "I would never tell him anything personal. We saw that with Nele. She talked about some problems and he called her parents." (Nizreen, 14)

In general, children are positive towards their teachers. This is certainly true for children in kindergarten and primary school. In secondary education, the attitude towards the teacher has a lot to do with who the teacher is and how he/she relates to the pupils. A strong theme in pupils' accounts is the value of teachers who 'understand' them.

"At Christmas, I had 83% and now at Easter, I had 87%. So I am becoming better and better!" (Liz, 13)

Children of all ages talk about being evaluated and the feedback they experience. They think it is very important to be appreciated for what they do.

Social relationships with other children and young people

They are being pushed by two bigger children who are running in the playground. The girl cries. Yasmine weeps. When I come closer, she says: "Friend". (observation Yasmine, 6)

In all the stories, we see that children with a disability have friends in and outside the classroom. Beside support from their friends, playing together is very important to them. Children look forward to seeing each other. Friends are an important motivation behind going to school (Whitakker, Kenworthy, & Crabtree, 1998). Disabled pupils have their own preferences. Reciprocity is an important factor in recognising friendship.

"I was punished because I threw sand in Hanne's eyes." (Arash, 5)

Pupils acquire (out of necessity) the ability to defend themselves. Their regular environment demands that they deal with expectations of and questions from others. Friendships matter to children, their parents and teachers because they provide children with the opportunity to develop important skills and attitudes and, perhaps most important, they enhance the quality of life for children and their families (Meyer et al., 1998).

"Nina walks around the whole time. She comes to Flo and takes her by the neck. Fortunately, the teacher has seen it. Then Nina says something bad to me too: 'Stupid scissors!'", she says, "If you don't say what you want to say, I will cut your ears!" Then she comes with her scissors, the teacher stops her before my ear is gone." (Martha, 8)

The children also talk about their negative experiences. There are stories of loneliness of being an outsider or a curiosity. At certain moments children don't feel at ease with their peers.

Help and support in the class and at school

- **Who gives support?**

The way the support is provided differs a lot depending on each child's situation.

"I can count on the help of other students. Some more than others. I think that everybody does it, not always and some are more motivated than others. The pupil who sits next to me always takes my books. My friends also help a lot. Ann doesn't mind. Nobody really minds, but there are students who don't like to do it." (Liz, 13)

A lot of help comes from classmates. This either happens very spontaneously or when the pupil with special needs asks for help. Sometimes the class uses a structured system to give support as a buddy (Snell & Janney, 2000). Children can have an influence on the help they get.

Sometimes there are support people in the classroom to help. The type and frequency of support depends on several factors. Some children need very little extra support except from the teacher and the classmates. Others have full-time support. Some receive individual support, in or outside the classroom. There are several systems in which children can get extra people to help: special educators, personal assistants through direct payment, volunteers, etc. This does not matter for the children: they are all seen as people who help them.

"Marjolein comes to help me in class. She also works with other children. She gives me some extra explanation if I need it." (Yentl, 11)

In some cases, the support is not exclusively for the disabled child. Every pupil in class can ask questions or receive help. Some of the support workers also go home with the children.

- **How do children experience this extra support?**

"It is good that Miss Isabelle comes to help, otherwise Miss Kathleen [the teacher] would cry!" (William, 5)

Most of the children think very positively about this. The support is related to positive consequences that go along with the help. They can do more work. Their classmates have to do less for them. It is easier for children to participate in the activities with their peers.

"I need help on Mondays, it's not my day. The other days, I'm ok. I can do a lot myself." (Kathy, 10)

Some children are very explicit about doing things on their own. They want to do things independently as much as possible. Children with a disability spend a large amount of their time in the company of adults and in social spaces where adults are actively present.

"If my special educator comes in lessons I like a lot, it's no fun to go out. When she comes during art class, I don't like to go with her." (Martha, 8)

If the help of the support person implies they have to miss things that are fun, children do not like help either.

"With every new adaptation, I am a little bit scared. I know I have to work like that, otherwise it's not possible for me. I have to explain that lots of times to other classmates and teachers. My assistant helps me do that, she tells them I can't participate if I can't do it my way. I will never be able to type fast and blind. I'm scared to be the exception." (Nizreen, 14)

Negative reactions of classmates can influence the way children experience extra support or adaptations. If peers are jealous, it is difficult for them. They do not want to be an exception. This becomes even more important when they grow older.

Therapy

"I don't like physical therapy. I'm sick of it. It takes a lot of effort. I know it is necessary for my muscles. I like occupational therapy. She helps me to write and count. I like that." (William, 5)

Most of the participants receive therapy such as physical, speech and occupational therapy. The therapists come to school or the children go to them after school hours. If we look at some combinations of school and therapy we see that the weekly programme for children can become very demanding.

Looking to the future

"I don't know what it will be like in secondary school. It will all be new. I hope the teachers will understand me there." (Yentl, 11)

"When I go to primary school, I will get a big satchel and homework!" (Arash, 5)

Children with a disability have a lot of ideas of what is going to happen to them in school, especially when they are in a transition period. They appear to be looking forward to certain subjects but we could feel some tensions, too.

Liz (13) will do something with her computer. She likes to work with it and is good on it, too.

William (5) will become a father and a waiter.

Most of the children have ideas about what they want to do when they become adults. They are inspired by their talents. They fall back on the subjects they are good at or on their personal interests. Young people, in particular, have a pretty good idea about this (Burchardt, 2004).

2.6. Conclusions and discussion

Through the research material, we learn a lot from the perspective of children with a disability. We would like to bring more depth in relation to two emergent themes. They give us valuable insights in how children think and experience their position in mainstream education.

First of all, this material shows that it is important to meet children and find out their views about education. It is a different perspective from that of parents, teachers, professionals, etc. (Lincoln, 1995). The respondents touch upon a lot of things that adults worry about in the

context of inclusive education – for example self-esteem, support, etc. (Van Hove, Mortier, & De Schauwer, 2005). It is essential to take into account the information received from children, regardless of their age and/or disability.

Most of the children have a (long) personal history of persisting and surviving from the day they are born, sometimes going through several schools and education systems. They are able to communicate their feelings and experiences about their lives at school. Given that young people are active managers of their situation, parents and schools should consult them about their educational program and the kinds of support they need. Such an approach is consistent with the rights of children to have a say in decisions which affect them (United Nations, 1992).

The second conclusion refers to the way children are talking about themselves and their (dis)abilities. The children are blurring boundaries that are set for them through the school system and their label(s). They are doing this without destroying bridges with the concept of support. The children are in a constant stream of playing within certain social expectations and they live in between the ‘regular-school-world’ and the ‘world as made for them with their label’. We recognise what Julie Allan (1999, p. 48) describes:

“Transgression allows individuals to peer over the edge of their limits, but also the impossibility of removing them. (...) They need not to reject their gendered or disabled identities, but can choose to vary the way in which they repeat their performances, cultivating an identity which is always in process.”

The data indicate that children focus on their strengths and capabilities. Working with children in a positive way on what they can and want to do can be an important tool. This is in contrast with the policy of approaching, orienting and classifying children on the basis of their labels. At the moment, there is no opportunity in Flanders to talk about the capabilities of disabled children, either in education or in welfare.

“This reinforces essentialist medical model perspectives, which concentrate on the deficits of children. (...) Detailed arguments about test scores, relative costs and diagnostic labels carry far more weight than the right of a child to belong or be accepted” (Whittaker & Kenworthy, 2000, p.228).

The children with a disability want to give correct and useful information about how to handle their labels. They do not only work with disability-related information. Parents, teachers, peers, support staff, therapists, etc. should take an overall view of the child's life in various contexts. This gives varied information about the personality and characteristics of the child.

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Chapter 3

Perspectives of parents²

² Based on: Van Hove, G., De Schauwer, E., Mortier, K., Bosteels, S., Desnerck, G., & Van Loon, J. (2009). Working with mothers and fathers of children with disabilities: Metaphors used by parents in a continuing dialogue. *European Early Childhood Education Research Journal*, 17(2), 187-201.

Het was een koude wintermiddag. Er werd weer eens een jongetje geboren. Er waren die dag al veel jongetjes geboren. Het ene na het andere. Hij is anders zei de moeder. Ja, zei de vader, hij is anders. Dan zeggen ze toch, zei de moeder. Ja, dat zeggen ze. Geloof je ze niet?, vroeg de vader. Ik zie het niet, zei de moeder. Ik ook niet, zei de vader. Maar het is wel zo. Wat moeten we er mee?, vroeg de vader. Met hem?, vroeg de moeder. Neen, zei de vader. Met anders.

Ik weet het niet, zei de moeder. Ik ook niet, zei de vader. Misschien moeten we er niets mee, zei de moeder. Misschien, zei de vader. We weten het nog niet zo goed. Nog niet, zei de moeder. Zullen we het ooit weten? Ik weet het niet, zei de moeder. We weten niet veel, zei de vader. Neen, zei de moeder. Hij is van ons, zei de moeder. Ja, zei de vader, dat weten we wel. En hij is zacht. Heel zacht, zei de vader. En hij ruikt lekker en geeft warmte, zei de moeder. Heerlijk, zei de vader. En hij heet Knaap. Of Knaapje, zei de moeder. Ja, zei de vader. Dat weten we wel. Het is een goed begin, zei de moeder. Ja, zei de vader, het is een goed begin.

It was a cold winter afternoon. There was a little boy again born. There were that day already many little boys born. The one after the other. He is different, the mother said. Yes, the father said, he is different. This is what they tell us, the mother said. Yes, that is what they say. Don't you believe them?, the father asked. I do not see it, the mother said. Me neither, the father said. But it is like that.

What do we have to do?, the father asked. With him?, the mother asked. No, the father said. With different.

I don't know, the mother said. Me neither, the father said. Perhaps we don't have to do anything, the mother said. Perhaps, the father said. We don't know yet very well. Not yet, the mother said. Will we ever know? I don't know, the mother said. We do not know much, the father said. No, the mother said. He is ours, the mother said. Yes, the father said, that we know. And he is gentle. Very gentle, the father said. And he smells nicely and gives warmth, the mother said. Deliciously, the father said. And he is called Knaap. Or little Knaap, the mother said. Yes, the father said. That we know. It is a good beginning, the mother said. Yes, the father said, it is a good beginning.

(Knaap, Geert the Kockere and Johan Devrome, 2003)

Abstract

Within this article we will introduce some metaphors as they were developed and used by mothers and fathers we worked with: the traveller, the warrior, the builder of bridges, the discoverer, the trainer/teacher, the in-between-er, the manager? We will position these metaphors as tools parents are using in their confrontation with normalising discourses of disability and education. In this sense mothers and fathers of disabled children can be seen as 'parents on the margins' from whom we can learn a lot about parenting in general. In that sense the metaphors we will present can be situated as a meta level parents present in their continuing process of reflection on their living together with their children with disabilities.

3.1. Background

Fathers/mothers of children with disabilities have always taken a unique – and sometimes controversial – position in the history of care. Fathers were often absent for a large part in this history or they were portrayed as onlookers who were unable to talk about their feelings and decided to immerse themselves in their jobs. Mothers have taken up all kinds of positions: some were overprotective and were accused of building a symbiotic relationship with their children. As a consequence of this symbiotic relationship the mothers continued to treat their children as small children, even when they were adolescents and young grown-ups. These mothers were also accused of the fact that too often they were speaking for their children instead of letting them speak for themselves. Other mothers however were described as 'fridge mothers' who were unable to bond emotionally with their child. For a while this last instance was even regarded in some psychoanalytical circles as a possible cause for the label 'autism' that was attached to some children (Van Hove, De Belie & De Waele, 2002). Furthermore, clinicians called the entire family of a child with a disability a 'handicapped family'. Due to the frame of mind of these clinicians, entire generations of young care givers received their training with images such as 'the neurotic parent', 'the suffering parent', 'the dysfunctional parent' and 'the powerless parent' (Ferguson, 2001, pp. 379-384). It is clear that the concept outlined above discredits those fathers and mothers who in the course of history have stood on the barricades, in their own environment or in wider society, and tried to improve the quality of life of their children and/or secure a place in society for them.

The tide is clearly turning. People involved in training and research are increasingly faced with the fact that the old 'clinical view' fails to understand some fathers/mothers. Goode (1995), for example, maintains that professionals must be aware that the parental and familial understanding of children encompasses considerable complexity and depth. Families come to attach meanings to the actions of their child through participation in shared routines. These constituted a broad base of knowledge from which to access the actions of the child. Professional

assessments inevitably defer to the knowledge of families. On the other hand, many new forms of support now take their departure from a close cooperation as equal partners with fathers/mothers and the natural network (De Belie & Van Hove, 2005; Fisher & Goodley, 2007; Landesman, 2003; Read, 2000; Ryan, 2005 and Ryan & Runswick-Cole, 2008). Pippa Murray (2000, p. 683) describes this 'partnership' as follows: "... I am referring to relationships within which my son was positively valued in addition to being central and of foremost importance; where, in the light of his medical condition, his learning and communication difficulties, my parental knowledge was seen as crucial to forming and maintaining a relationship with him; where different roles with regard to my son were recognised and the boundaries between those roles respected by all parties; and finally, and most importantly, they were relationships with which my son was happy ..." Fathers/mothers themselves also realise more and more that their perspective is important and that it has a great deal of influence on the path their child will take (Dan Habib; Ferguson, 2003). The above themes, namely: the need for changed images so fathers and mothers are better understood and 'to work together in equality' will be at the heart of this article.

3.2. Research context

Writing this article was made possible by using empiric data from a partnership of researchers that have an extremely close relationship with fathers/mothers of children with disabilities. The research material for this article was sourced from three main research projects:

- For the last ten years the first three authors have been closely involved, in the form of action research, with a family project in Flanders (Parents for Inclusion) which advocates that families decide for their child with special needs – and this often against professional advice – to be educated in a mainstream school (Van Hove, Roets, Mortier, De Schauwer, Leroy and Broekaert, 2008).
- Bosteels and Desnerck have held in-depth interviews for an lengthy research project with the fathers/mothers of the first

generation of children that were given a cochlear implant in Flanders. The fact that young fathers/mothers of small children have to make a decision so early in life about this extremely invasive procedure is not without consequences.

- Van Loon has been involved since 1994, both in practice and via research, with the deinstitutionalisation of more than 400 children and adults with intellectual disabilities in the region near the Dutch-Belgian border. These children and adults no longer live together on a closed campus in large groups. They live in society, either by themselves, in small groups or in foster families. It is clear that this process has had a huge impact on the families involved.

These three starting points for research show that the authors of this article work predominantly with 'fathers/mothers in the frontline'. The situations researched can be described as 'extreme cases' (Yin, 1994). The situations of these families and the choices they make therefore are used as 'field tests' by practice workers and researchers to look at certain attitudes and reactions in a different light and to start a dialogue with the fathers/mothers to see how working together can be implemented.

3.3. Methodology

As non-linguists we still dared to collect images and metaphors as research material given to us by fathers/mothers. For our work with metaphors we found the work by Danforth (2008) very helpful, who rightly states that "the analysis of metaphors within cognition and language has to be seen as one way to illuminate and interrogate the social meanings of disabilities that are produced within cultural activity..." (p. 386). Because of his study on metaphors which are used in the US to acquire a better understanding of behavioural and emotional problems of children, he already had extensive experience in this matter. In a previously published article about using the 'machine metaphor' to study autism (Danforth & Naraian, 2007) he describes the use of metaphors for the (pedagogical) sciences as follows: "... Traditionally,

metaphor has been viewed a literary trope standing in opposition to literal forms of writing in the natural and social sciences. In recent decades, however, a multi-disciplinary field of cognitive linguistic research has developed. This research finds metaphor at the heart of both everyday and scientific thinking. Metaphor is understood to be vital to the development of useful theories within the sciences ..."

The metaphors for this article were gathered by using the 'key incidents' method (Emerson, 2004). Key incidents are events or observations that help to open up significant, often complex lines of conceptual development (Emerson, 2004, p. 456). It is a research strategy that is coupled to ethnography from the actual experience of many ethnographers that their analyses were strongly shaped by particularly telling or revealing incidents or events that they observed and recorded (Emerson, 2004, p. 459). A key incident attracts a particular field researcher's immediate interest, even if what occurred was mundane and ordinary to participants (Emerson, 2004, p. 469). This 'interest' is not a full-blown, clearly articulated theoretical claim, but a more intuitive, theoretically sensitive conviction that something intriguing has just taken place. These key incidents are helpful for a naturalistic analysis that is necessarily open-ended and emergent, tied to and deriving from specific pieces of what has been seen, heard and recorded (Emerson, 2004, p. 458). It helps the 'naturalistic retroduction' moving back and forth between observations (here: images and metaphors) and theory (here: about parenting and children with disabilities and about power mechanisms between professionals and parents). So, original theoretical statements are modified to fit observations, and observations are collected that are relevant to the emerging theory.

3.4. Research findings

Below we will introduce to the reader the metaphors used by fathers/mothers. We will embed this metaphorical description in the key incidents where we were able to discover these metaphors.

The traveller

"My child is my voyage around the world, so I am a world traveller." is one of the extraordinary positions presented to us by a mother. It turned out that she and her partner had their first child at a very young age. The pregnancy was not planned, on the contrary, both parents – who were in their final year of secondary education when the pregnancy occurred – had just made plans to take a gap year to explore the world after they finished their secondary school. With the arrival of their child these plans became rather less practicable. Moreover, when it turned out that the baby was born with various impairments these wonderful plans became totally unrealistic. And still... talking to the mother later on we learned that these young people didn't throw in the towel. Living in Belgium they found that they received too little information about supporting and stimulating their child, so they began to look for it across the border. Eventually they found a treatment centre in the USA where they travelled to with their child. They were admitted to an intensive and short support programme. Our young world travellers were not to be stopped and they obtained permission to move into a mobile home next to the university campus, where the treatment centre was based, for the duration of the programme. This experience laid, as it were, the foundation for later family excursions into Europe, usually for the purpose of some kind of treatment/support for their child.

Tintin in the land of care providers

Fathers/mothers indicate that the moment their child was diagnosed, they landed in a completely 'different' world, a new territory. They had – just as other fathers/mothers – so many dreams and expectations for their child and suddenly all that changed. They came into contact with professional care where they seemed to have all the 'answers' to the questions concerning the life of their child: medical care, school, nutrition, leisure time, therapy, communication, etc. The parent however always remains the gatekeeper. They are given information and it's their decision: does this actually help my child? Is it in his/her interest? One mother says about this: "When the time came for my daughter to go school, we followed the path that we thought we should follow. It was very difficult to subject her to an intelligence test. A multi-disciplinary

team referred her to a special school for 'children with severe intellectual disability'. They gave us an overriding motive: our daughter had multiple medical problems. Therefore the school should have a well-equipped medical department. (...) We then went back to the multidisciplinary team with a request to have our daughter reassigned. The gap between what she was doing at home and what the school was offering became too big. For the two years extended pre-primary classes we wanted her in a special school for 'children with physical impairments', where they could give her maximum support regarding communication. The school that agreed to try it, warned us from the start: it will probably not be for longer than two years. Your daughter doesn't really fit in our target group, she shows no interest, the gap between her and the other children is too big... We saw her make huge progress and she really tried her best in those two years to catch up, but it wasn't enough for the school. Our daughter didn't make the grade for standard primary schooling in special education."

The diagnosis of their child is often the first time that fathers/mothers are confronted with a position as 'user/client' within the care for people with disabilities. For many of them this goes together with a significant feeling of dependence as regards professional care. From conversations with fathers/mothers it seems they are given a great deal of information from a professional angle. They are told about the extent of their child's problems, given recommendations about what is best for their child and which therapy they should go for, etc. In this it is obvious that most of the professional advice is predominantly 'defect-oriented'. This is often confusing for some fathers/mothers because they have to find a place for their child as well as themselves on this course that has been mapped out for them. One mother described her confusion literally after being given a diagnosis: "When I was driving home I looked in my rear-view mirror and wondered if my son, sitting there in his car seat, was still the same after the new diagnosis."

However, this is not the first time that fathers/mothers are confronted with the fact that their child is different. For all children there is a history of many concerns, questions and making choices prior to the diagnosis. Fathers/mothers build up a defence mechanism of sorts in order to deal with the (negative) news about their child. They draw strength from the

progress and (slow) evolution they see in their child, in spite of all the question marks and problems. They live with and care for their child by trial and error, day after day.

The manager

During some discussion evenings between fathers/mothers and professionals, guided by the first author, we had the privilege of meeting a very special father. He introduced himself straightaway as follows: "I am X, father and manager of John, my son who has a serious cognitive impairment and mental health problems." During the discussion evenings X told his story with a great deal of emotion and energy: It all started for him in the first (special) day care centre where he took his son. He soon realised that he had arrived in 'a new world' (his words), a world with very specific terminology and conventions. Multi-disciplinary team, treatment planning meeting, 'snoezelen', ... are examples of this new terminology. He also soon realised that sometimes changes were made in the daily routine after this had been discussed in a meeting ... without inviting the fathers/mothers. They were informed afterwards via 'the communication notebook' (another new word again). If they didn't quite understand it they could ask the 'counselling assistant' to explain; if they didn't agree with the changes they had to convey their objections to the 'remedial educationalist', who would then raise it at the next meeting, usually a few weeks later... When after a time it turned out that quite a few changes were being made and that he did not really approve of these changes, but they proved to be irreversible (as decided in a meeting after considering the queries and objections), this father decided that enough was enough. He started a kind of protest action and parked himself - without having made an appointment - near the office of the principal (who initially was too busy to see him) until he was granted a short interview. In this interview the father made the following demands: "No meetings will take place here about my son without me attending in person. I also want to know prior to the meeting which points on the agenda relate to my son so that I can be prepared... or else I will remove my son from this day care centre right now." At that moment quite a few reasons were dug up why it would not be such a good idea for the father to attend (difficult terms were used at the meetings, it would be emotionally very demanding for the father, the staff was not used to

having fathers/mothers at their work meetings, the other fathers/mothers might start to ask questions too, etc.). The father stuck to his guns and since then he lives with a 'double agenda': his own agenda (he works in a creative sector where arranging appointments and meetings is already extremely flexible) and the agenda of his son. The second agenda always has priority and quite often he has to rearrange his own meetings in order to accommodate the second agenda.

The trainer/teacher

One of the mothers we have a close working relationship with as regards inclusive education was at the start of her professional career an extremely talented and promising research assistant at a university. In addition to the research she conducted in preparation of a doctorate, she was frequently asked by her promotor to work together with small groups of students in research seminars. This life came to a halt when she became a mother and especially because she became the mother of a son with Down syndrome. After an initially confusing time she and her husband started to look for solutions that fit in with the very clear education project that they had in mind. In this project language, solidarity, cooperation, a questioning and searching frame of mind, etc. played an important part. In their quest this family joined the local Down Syndrome Association and Parents for Inclusion. And so second career began for this mother. She first gave lectures about what their family life was like with a son with a disability. Then, in a next phase, she participated in research based on the way in which families in Flanders make choices with/for their children with disabilities. In her activities at the Down Syndrome Association she even went one step further: she got the opportunity to give talks to GP's in training about Down syndrome as experienced from the parents' perspective. We should now go back a little in the history. It was precisely some doctors that the mother heavily collided with soon after her son was born. For instance, she was advised not to breastfeed (children with Down syndrome were supposed to be too weak for this) and she was incensed about some of the advice she was given in some therapeutic centres... But now she could present an information package about Down syndrome to young doctors in training and talk freely about the sensitive issues that arise in the communication with fathers/mothers. "I feel like a proper teacher", she often says, "with

this distinction that I am not speaking from my knowledge as a Master of Science but about my personal life story and emotions."

It is clear that working with a large group of people around a child – professionals or otherwise – made experts in certain fields of the fathers/mothers going through the education process. A 'father-trainer' says: "It is a sort of timeline, at different stages in the education process of our daughter different people have been involved. Initially they did not need anybody else in the classroom, a family support worker was involved and if there were special activities (school trip) my wife or I sometimes went along to help. Later on we were working according to the principle that we would pass on everything that could be passed on. And then we had student teachers joining us and volunteers and other fathers/mothers also gave their support for certain activities."

The bridge builder

In Belgium we have – just as in some other Western countries – the system of a personal budget (in addition to the still prevalent collective provisions for persons with disabilities who need support). This system of financing means that the support for people with special needs is no longer arranged via collective care and support systems. The fathers/mothers of a child with a disability have a budget at their disposal and can use this to hire people or to pay for services for their child.

All this means that families can find the services that are needed to best suit their family, but on the other hand this brings with it a great deal of responsibility for them. They suddenly find themselves to be employers, something which is not always easy to combine with their role as father and mother. With the many fathers/mothers that due to this new system find themselves in this position, we see that the way they go about it varies enormously. Time after time we have been enchanted by one of the mothers who describes herself in her new role as a 'bridge builder'. This mother/family manages to organise a 'Christmas party' every year to which everyone who means something to the family is invited. Due to the warm atmosphere in this family all year long, many people always turn up at this party. This includes people (e.g. teachers) who are no

longer directly involved in the support of the child. In this way the mother succeeds to involve the 'topsupporters' who will use their expertise to support the situation at school. This elicited the reaction of one of the teachers that "it is really comfortable to work in a class if there is this kind of support, particularly because they can help other children too". While we were working with this mother it became clearer all the time what she meant with her bridge-building metaphor. She ensures all parties feel comfortable and lets people know that they are appreciated and welcome, in a way that is natural and without being pushy, but it does happen and it makes an impression.

The tight-rope walker

Fathers/mothers are experts in the 'art of balancing': in the learning process they always have to look for a state of equilibrium. Two parents who often look to find a balance, describe it as follows: "You never know beforehand. You don't know either whether her impairment is the reason for what she cannot achieve. You are not sure what will be possible and what will not be possible. It is a matter of finding a balance and to push out the frontiers all the time. We encourage the nursery to try out things with our daughter. We have clear expectations about this, but we don't want to push it. We sometimes have to stop and think about what should come first, we must not expect things to happen all at once."

We see fathers/mothers also constantly balancing between 'normal' and 'special'. How do I regard my child? What does my child need? Which terms do I use when I talk about my child? What part does my child play in our family and wider society? Many fathers/mothers imply that they keep this as normal as possible, usually with their other children as reference. However, their child will often need extra attention, care and support. The father of Jan describes this as follows: "Jan is a boy who will always need extra care from us. All his life we have to consider carefully what is possible for him and how we can help him. He is definitely ill more often than our other children. But we still try to treat him the same as our other children whenever possible. We don't want him to become a spoiled brat. He is the oldest child of the family. The other children grew up with him. We always try to include him as much as possible and

sometimes we will adjust the activities somewhat to make it easier for him."

The strategist/diplomat

Fathers/mothers often turn out to be seasoned diplomats. Communication is a recurring theme here. And in this communication the 'circumspection' in the 'open communication' is evident. Fathers/mothers often opt for an extremely strategic approach because of their 'vulnerable position'. One of the mothers we are working with, states: "I think that's why sometimes I think and act very strategically (from whom do I definitely need support) because call it what you want, we are faced with a policy of tolerance in many places. Sometimes you will go and have a one-to-one chat with the principal, or you will raise something with the care coordinator or the assistants... You always have to weigh up the pros and cons, because after all our child is in a more difficult position. Other fathers/mothers tend to voice their opinion freely, but we, we have to think it over first."

Some fathers/mothers in this position are therefore always looking for strategic allies. Almost automatically they come into contact with all kinds of professionals, therapists, experts, etc. They are looking for an attentive ear, people that make them feel at ease, people that will not judge them but help them with questions they have about their child. We see that fathers/mothers also try to find an ally who will help them to defend and support their child. Some fathers/mothers don't want to be on their own and don't have the required know-how about a child with a disability.

The battler

Life with a child with a disability doesn't always run smoothly. In our opinion too little attention is paid to the situation of families with children with 'non/invisible disabilities'. The beautiful child with autism, the pretty child who is hearing impaired, the adorable toddler with a developmental delay,... they often don't meet the expectations of the environment. And just because 'it doesn't show', other people often judge wrongly and think that the child is 'obstinate' or 'not brought up

properly' or ... This is the case with Mathias, a good-looking boy who already from the first steps he was expected to make in his development could not (quite) deliver or who gets extremely anxious if he is expected to do something which he finds impossible to do. Initially he often caused his parents to feel 'disillusioned' too, but once they realised there was indeed a 'problem' they – especially the mother – stood on the barricades for him. The mother went even further and indicated that she was willing to go on the 'warpath' for her child. And a confrontation with this 'mother on the warpath' is definitely not easy. She is extremely gifted in what we can call 'associative thinking' and can make connections in less than no time. Furthermore, she has studied law so when pushed to the limit she will put on a different hat and threaten with lawsuits and complaints... Our 'mother on the warpath' fights above all for her son to have the same rights – regarding the right to diversity and support – as children with obvious, visible disabilities.

Fathers/mothers of children with disabilities are obliged to have a list of all the arguments for the choices they make and to explain them to the outside world on various occasions. Their choices are often questioned and fathers/mothers feel that they have to convince people of their choice over and over again. The mother of Mathias writes in an e-mail: "What rights do I actually have here? Mathias has been diagnosed and that has consequences, but it seems that I am regarded as a mother who is being difficult and they just ignore me. I suppose their argument is that he attends a normal school and is in the fifth year, so he should be fine! This is very frustrating for me, because his autism won't disappear with age. When will we finally get the enforceable rights for our child? Or must we continue to be dependent on the goodwill of the professionals?"

Fathers/mothers fight and will go on fighting for what they consider to be important for their son or daughter, based on the belief in the possibilities of their child. They 'get used' to dealing with opposition. They try to change and adjust situations to get what they think their child needs. If this is not successful they'll look for other ways. Fathers/mothers often experience that they (and their child) are isolated. One of the fathers we work with, says: "If I get the feeling that they would like to put her somewhere else they've got the wrong man. It will make me react in a contrary way. I don't want to push things. If they ask

me in a rational and pleasant way I will comply, but not like that, I've made my decision and I won't change my mind. That is how I am. And to simply say that is the rule here... Well, rules are there to be changed."

The explorer

At the University we often ask fathers/mothers to take part in lectures and presentations for students. One of the mothers we asked a few years ago for the first time to talk about her son and family did so, but she was very nervous about it. She found it quite daunting to be faced with the students and university. "I myself am just a nurse", she kept repeating... However, she had collected a great deal of material, photographs, stories and anecdotes about her child. She indicated that secretly she dreamt of making them into a book. When we met later on, this mother seemed to have acquired a taste for studying and followed a Bachelor course in Family Sciences. She often mentions that in all this she discovered 'many talents in herself'. Earlier inhibitions disappeared to be replaced by reflections about the path taken by her own children, but she also had further thoughts and questions about education. In our most recent meetings our 'explorer' stated that she wanted to go for a masters degree after her Bachelor course, because her new insights raised as many new questions and she definitely wanted to further explore these. She also says that she feels so much stronger now. That she used to be quite timid and hardly dared speak her mind, but that through the years, due to the situation with her son, she became much more self-assured. That she felt totally at ease in a meeting with the principal. Earlier on she wouldn't even have gone there. So, in addition to discovering qualities in her son she also discovered a number of talents in herself that up till then had been uncultivated. Isarin (2004) states that the relationship between a mother and her child with a disability is not always reciprocal. Usually the relationship will still be regarded as being meaningful by the mother. The child wants to be taken as it is. The child touches the mother by how it is and what it is. The child changes her, her relationships and her view of and approach to life.

3.5. Interpretation and discussion

First and foremost we want to stress that we do not want to judge the value of any of the metaphors whatsoever. It is not about the right or wrong choices made by fathers/mothers here, but about attitudes and choices that are needed to make it possible for the fathers/mothers 'to live through another day'. It is not for nothing that Goodley calls them the 'philosophers of the day' (Fisher & Goodley, 2007; Goodley, 2007).

We are convinced of the fact that the metaphors we were able to collect were introduced in our communication by the fathers/mothers consciously and purposefully to make their own positions clear. In this way they try to build a barrier against the preconceived ideas of 'the parents' that were installed over the years. In this we follow Steen (2007) who states that there is indeed a relation between the language used and cognitive processes.

Some positions (Maccartney, 2008) (e.g. the manager – the warrior) are explicitly taken up by the fathers/mothers to protest against the defectological/deficit discourses used by some professionals (and their systems) for their children. Goodley (2007) introduces the work of Deleuze and Guattari to show that many practices of social care are based on binary thinking, where children with disabilities are put in contrast with classifications such as 'healthy', 'normal' and 'fully participating' (Winance, 2007; Maccartney, 2008). These practices threaten to territorialise the mind, self and body. It is from these defectological discourses stated in the position 'Tintin in the land of care providers' that the parents are given advice about education, schooling, therapy, etc. that threatens to put them on the sideline. This advice is given by experts who underline their expert status by their specific techniques of classification, assessment and labelling and thus ignore the expertise of the fathers/mothers. It is also these processes that make the children end up in 'a special circuit', a circuit where because of their special needs they are seen as requiring a different 'treatment' than their 'normal' peers. With all this going on we see some fathers/mothers revolt and take on the fight.

A number of other positions (the bridge builder, the diplomat, the tight-rope walker) teach us about fathers/mothers who do not revolt as such but use 'clever strategies' to retain more control over the education of their child. These positions could be compared with a kind of 'working through' as introduced by Braidotti (2004, p. 29). This author describes the process in which people take up a position where on the one hand they do what is expected of them. On the other hand people make their own assessment of the position and look for new codes and opportunities. The fathers/mothers from our study use this very deliberately to improve the participation of their child, e.g. by finding 'important allies', by networking with people who 'can help' to realise the plan for their child, by avoiding conflicts with persons and agencies that they want to be on their side when they are trying to effect more participation for their children. Fathers/mothers are transformed in their position as a parent. This cannot just be described in terms of 'learning to live with' their child with a disability. The previous history and their experiences 'define' them in a certain way as a parent. "Conditions for such a transformation are for the fathers/mothers: the ability to accept their child as it is, with the intention to make the best of it, the conviction that this father/motherhood is meaningful, building up confidence and the ability to live with uncertainty." (Isarin, 2004, p. 154).

There are also positions (the traveller – the explorer) which show that people, in their role as 'father/mother' as well as in their personal development, sometimes draw on a special source of energy and consequently are far away from the linear thought that 'insecurity paralyses' (Fisher & Goodley, 2007; Goodley, 2007). These fathers/mothers will start searching, go on a journey (literally and figuratively speaking) and take unexpected steps for their child and themselves. They bring us to the concept of 'nomadism' as outlined by Braidotti (2004, p. 40): these fathers/mothers do not renounce their 'old self', but exploit the situation with their child to reinvent themselves (and their family). They show us that they possess exceptional intelligence and creativity. They show us that they excel themselves and at the same time get modestly flustered when they look at their own 'achievements', their own way of grasping opportunities, their own way of developing and exceeding their own expectations.

Fully in line with the latest versions of the labelling theory (Link, Cullen, Struening, Shrout, & Dohrenwend, 1989) there are also fathers/mothers who choose a position as trainer/teacher. They don't place themselves – as in earlier versions of the labelling theory – in a kind of passive victim position, feeling they cannot compete with the people who attach a label to their children (with all the negative consequences of this label as a result). On the contrary, they want to exploit the special situation of their child to supply information in order to prepare (future) professionals for a relationship with their children.

Finally we would like to make it clear that the fathers/mothers from our study do not let themselves being pinned down in one single position. They tend to tell us first about the position they find strategically important; however, most of them are flexible enough to fulfil various roles. In this way fathers/mothers show us how 'revolutionary' they set to work, revolutionary in the meaning of the description by Deleuze and Guattari (Allan, 2008, pp. 67-69): "the action by which something or someone continues to 'become' other (...) involving the invention of new forms of subjectivity and new connections (...) while continuing to be what they are."

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Chapter 4

Perspectives of teachers on inclusive education³

³ Based on De Schauwer, E., Vandekinderen, C., & Van de Putte, I. (2011). *Voorbij de vraagtekens?! Perspectieven van leraren op inclusief onderwijs*. Antwerpen: Garant.

Don't say you are right too often, teacher.
Let the learners realize it.
Don't push the truth:
It's not good for it.
Listen while you speak.
(B.Brecht, 1953)

Abstract

To be a teacher is an important, exciting and demanding profession in our society. It asks a lot of responsibility to educate children and young people to become versatile, vocal and critical citizens. The teacher is always placed for new challenges and demands. Addressing a diverse audience of pupils/students within education is one of those. The latter is creating quite a dust whirl in Flanders, including response to the Framework for Learning Care (Leerzorgkader) under Minister Vandenbroucke (2007). We fail to structurally anchor inclusive education into our legislation. Yet we hear the voice of teachers with experience in the classroom not much in this discussion. Based on interviews with 17 teachers from kindergarten, primary and secondary education, we tell how they make inclusion work. The reoccurring themes, common patterns and key moments of these stories are then further examined. We explore in depth the arrival of the child with a disability at school, uncertainties of teachers, participation within the classroom, social relationships, communication and team cooperation and the role of support. How can we learn from the experiences of teachers that have already invested in several processes of inclusive education?

4.1. Way of working

The association 'Parents for Inclusion' came up with the idea to do something with the stories of the teachers, who had a successful school year with their son or daughter. They brought together a number of teachers who wanted to tell about how they had experienced and shaped the process of inclusive education. Furthermore, we gathered teachers through our own practices in coaching inclusion teams, and working with students who support children with disabilities in regular education. We asked the teachers for an interview on the basis of the added value they saw in the presence of a child with disabilities in their classroom. These stories occur rarely in the foreground, but exactly these experiences can support other teachers in their quest. We started to collect these positive stories. This does not mean that it was all beer and skittles. During the interviews, the teachers went deeper into their disillusionment, doubt, fear, frustrations... because the diversity story was a complex subject with different interests, perspectives, uncertainties and obstacles.

The interviews were conducted by students of educational sciences Evelyne De Keyzer and Lize Verhoeven in the framework of their internship or master proof. We worked with semi-structured interviews. The themes in all the interviews dealt with: vision on education, the representation of the child with a disability, involvement of the child within the classroom, impact on teaching, building an individual learning path, team functioning around the child and dealing with support. The way of working was quite informally, teachers were allowed to speak freely. We asked teachers to focus on one school year and one concrete (inclusion) situation. They talked mainly about the everyday classroom practice including the classroom dynamics, didactics, cooperation with colleagues and parents, etc. All interviews were completely typed and played back to the teachers to change again, to articulate, to clarify and/or supplement. From these interviews, we have 17 stories chosen from teachers of kindergarten to secondary education with a strong variation in age, experience, education type, location, nature of the capacities of the child, support options, etc. Some

teachers were interviewed about the school year that just finished, other teachers told about a previous experience (maximum 5 years). Regarding one boy, we had the stories from two teachers and the principal of the school. That way we could show that inclusive education is not the case of a single individual; we wanted to accentuate the nature of inclusive education as a process.

We have done a thematic analysis on the stories. Each story was read several times and coded. For the analysis we followed an inductive and conceptual way of working such as Clarke's (2005) and Charmaz' (2006) method. Reoccurring themes, common patterns and key moments were identified by Caroline Vandekinderen. The themes were examined in respect of consistent patterns and exceptions. Then all three of us discussed the content and overlapping between the different themes. This led to 6 common aspects in the stories of the teachers which we worked out deeper. These aspects are: (1) the selection process of the teacher/school to meet the challenge of inclusive education, (2) teachers' uncertainties associated with the choice of inclusive education, (3) participation of the child with his/her own pathway within the classroom group, (4) influence of inclusion on the classroom climate and social relationships within the classroom group, (5) the communication and cooperation with the team around the child, and finally (6) the quest and the use of support in the class. We provided each theme with leading quotes to show how teachers experienced all this. The stories of kindergarten, primary, and secondary education are brought together, but the voice of the teacher is never far away.

We are aware of the fact that the interviewed teachers are not representative for all teachers in the system of education. The analysis has certainly not the intention to be complete nor is it the view of the possibilities that we ourselves experience within an inclusive classroom practice. Yet these stories and analysis provide valuable insights on how teachers committed to the struggle for inclusive education.

4.2. Analysis

4.2.1. Making a choice for a child?

As a teacher

In the stories, the teachers are divided into two groups about the fact whether or not they can choose for a child with a disability in their class. Some teachers find it is important that they can choose; in the end, the teacher has to do it. Within education there are already many choices where a teacher is not involved in. Otherwise it could have negative implications on the pupil with a disability and his/her classmates.

"During holidays, my principal phoned me to ask if I would have objections against Nizrien in my class. It seemed a nice challenge. I thought it was important that I was able to choose for it."
(Vouter, teacher of Nizrien, first grade of secondary school).

Other teachers had no choice and just did it. There was no time and space to doubt. They indicate that choice is also not possible for other pupils. Diversity is a reality of society, within the classroom teachers cannot ignore that.

"I took the class when the teacher became the principal. Caroline was just there. I was not asked if I agreed and maybe that was okay. As a young teacher I doubted about my abilities and I would have taken another ten years to try it. Now, I just did it!" (Antigone, teacher of Caroline, fifth – sixth year of primary school)

Teachers prepare themselves for the arrival of a child in their class. We see that the teacher first talk to the parents of the child about the child and what the parents expect from education. Why did they choose for inclusive education? The pragmatics of the class is immediately addressed. Teachers talk to their colleagues and observe in the classroom where the child follows classes. How is the child? Does the child disturb the classroom? What does the teacher? What are the expectations to the teacher? What additional investment is needed by the teacher? What support is available in the classroom? Exchange of information with other teachers is very important. There is also consulting with supporting services: the special educator, support workers from a direct budget, the

rehabilitation centre and/or the therapists that know the child (much longer). People find it important to gain an insight into the problems of the child and how they can handle it.

Within the school

Many teachers indicate that the question for inclusive education first comes to the director. He/she discusses this within the teachers' team. It is important that the commitment is carried by the school team, not just by one individual teacher. This does not mean that everyone has to agree but some people must be willing to put their shoulders under this project. This increases the growth opportunities in the longer term. Tineke describes this for Wiske in secondary education:

"Yes, that was asked during our teachers' meeting and not only to the teachers of the first year. It was also asked to the teachers in the second year. Now the director already talked with the third grade about Wiske going there." (Tineke, teacher of Wiske, first year of secondary school)

Many teachers realize that the choice for education is a choice of parents. It is not up to them to question that. Parents are usually better informed than the school itself. It is important to think why you want or do not want to cooperate as a school. Teachers stand behind the philosophy of inclusion: they believe that every child deserves opportunities to participate in education and to learn skills that are also needed later on in society. When deciding whether they want to work with a child, the social commitment of teachers and their vision on 'good' education are decisive factors. The child with a disability is a member of our society. The school is seen as the ultimate mini-society par excellence. Geert puts it as follows:

"The inclusion idea appeals to me greatly, because I see this wider than only the classroom. It is a societal matter. But it should start in the classroom, or the classroom is one of the ways in which it can start." (Geert, the principal of Jerom)

It is very important for a school to ask what is necessary. What are the needs? What are the concerns? Can the school offer what the child needs? Teachers accentuate that additional support is necessary. This is not only support for the child; teachers also expect concrete assistance in the provision of adaptations and shaping of individual educational plans.

Schools negotiate with the child's parents about who gives support and on how much support they can count.

Not all teachers of the team are behind the choice for inclusion. It is clear that teachers can grow in working with a child with a disability while the child has his/her way through the school. This can give quite some division among the members of the school team. The principal here often plays a crucial role in the bypass or redirecting of this protest.

"There are still teachers who question inclusion. The difference is that they do not know Emma and have no experience with her. They just see her in the playground and are having questions about her presence here. You don't need to look at inclusive education as a burden. I do not pay a lot of attention to colleagues who are doing that." (Caroline, teacher of Emma, first year of secondary school)

The choice of inclusive education is coherent with the school culture where care for children with special educational needs is well developed and receives a lot of attention. One can see working with these children as a challenge and will actively participate to give children all possible education opportunities in regular education.. There are several concerns. You should be aware of the fact that we cannot expect the same effort of every teacher. Teachers find it important to give an accurate picture of what the child can(not) do compared to the standard curriculum. The teachers are also concerned about the other children in class: everyone should receive sufficient attention. Filip says:

"The group of weak learners has grown so big, that it is not workable anymore. You also have the strong kids in that class, whom you should also monitor, because they also need plenty. Those are things that certainly should be guarded." (Filip, the teacher of Jerom, first year of primary school)

When the school makes a choice for a child with a disability and his/her family, this does not lead to a stream of children with special educational needs.

"When we receive another request, we will discuss this and we can only take our positive experiences with Yani in consideration." (Luc, teacher of Yani, third year of primary school).

What are limits towards inclusive education?

Many teachers indicate that much depends on the child with a disability. Each question for inclusive education should be looked at one child at a

time. Unknown is unloved. Teachers dare or can speak about the child they experienced in class, they are cautious towards other children. The school must consider the child and the conditions for the child to get started. How is the child in the classroom? How does the child handle his/her difference? What does the school need for this child? It is very important to get to know the child and work with him/her.

It is a condition for teachers that a child is evolving in a positive sense. If there is no learning, it is occupational therapy. The regular school must add value to the education process of the child.

"We have told her parents that if Jana has reached her ceiling, if we no longer bring her forward, then she cannot stay here too. We cannot keep her for 12 years in the same group level, because she likes to be at school. We want to be honest to the parents. As soon as a child doesn't make progress anymore, he/she must go somewhere else. " (Cathy, teacher of Jana, third year of primary school)

There is clearly a lot of fear for children with difficult behaviour. A child should be able to follow the regular functioning within a class group. If a child runs away all the time and is disturbing the work of other children, teachers see this simply not achievable within regular education. The child must be able to adapt to social rules and practices within the school. There are also questions about children who have difficulties in social contacts. Social relationships are regarded as one of the largest gains in inclusive education.

"If you, for example, get someone in the class where you don't really have contact with, I would find that much harder. With Hugo, you can make contact. If you ask a question, Hugo responds." (Eef, teacher of Hugo, third grade of secondary school)

Within the stories the teachers put limits on the work they can do themselves. The implementation of inclusive education cannot be completed without additional support. People expect more than the current support provided from education.

"Support is needed because they ask so much of teachers. With an special educator two hours a week, you cannot do inclusion. You need to observe each child. All data needs to be tracked. If you count all the extra work, providing individual educational plans, putting work on the computer, meeting with speech therapist... it must stop somewhere." (Ann, teacher of William, first grade of primary school)

There are also limits to how many children are welcome in one class. Teachers see a possibility for one child with a significant disability in class, but are cautious about a concentration of problems. It should all remain possible.

4.2.2. Forum for uncertainty

Acknowledge uncertainty

The doubts for teachers lie especially in the daily classroom practice. How will inclusive education be realized in this class with all these children? It is important to put these questions and fears openly on the table, because the information teachers get to their questions, affects their motivation to start.

"When we heard that the parents of Yani asked to come to our school, we had with the team a number of reservations and we addressed those, in question form to the parents. We received really proper answers, and I had the feeling: Yes, we should certainly try that." (Luc, teacher of Yani, third year of primary school).

It is crucial to create no taboos around these uncertainties, but go into conversation with people that know the child and the way of working within an inclusive classroom.

Uncertainty about...

Teachers have various questions. There is fear around the deficit(s) (and the medical complications). People feel they have no expertise and knowledge about that. Many questions are situated within the classroom practice. Can a teacher in the classroom continue to do what he/she did previously? What adaptations need to happen? How does a teacher shape an individual educational plan? What does this mean in the preparation of your lessons? Can the teacher give the child enough to prepare for future? There is also uncertainty about the relational aspects within the classroom. Can the teacher build a band with this child? Will the child understand him/her? Will the child will feel okay in the group and be accepted? How will the fellow pupils and their parents react?

Finally, we also see anxiety among the other adults who, together with the child come into the classroom. What influence will the support worker have on the teaching? Will that person check on the pedagogical approach?

There are no universally final answers. Every child and every situation has different needs. As a teacher you will follow each child individually on a path with ups and downs. The moments of uncertainty are natural for every teacher in an inclusion process. The uncertainty may and must be recognised, but it should not remain there. It is important that teachers get on with it. The space to experiment (and occasionally fail) must be very clearly communicated to teachers, such as a principal (ex-teacher) formulates:

"I expect every teacher to be open and try. They have to try and have the courage. They may fall, that's no problem, we will help to rectify them again, but they should dare to come out of their situation of certainty and control. I expect that from them." (Geert, principal of Jerom)

Some ways to handle uncertainties

All the teachers managed to overcome their uncertainties and in their conversations they talk about what helped them.

- ***You fall back on your skills as a teacher.***

The questions and doubts can be tackled by the realization that the work a teacher daily does for all their children also works for this particular child. This expertise will possibly be expanded or deepened, but *au fond* teachers already have a very rich arsenal with basic competencies to let children learn. Ann formulates:

"As a teacher you should be able to say: I am already a few years in this grade, I know my job and I will do my best. You must have a little faith in your own capacities. We all learned something new from William." (Ann, teacher of William, first grade of primary school)

Teachers search for a balance between dare rely on their experience and continue to think critically about their teaching style.

- ***Just do it!***

Teachers are more aware of their way of teaching, the applied forms of work, their didactic input, different learning styles of the students... The initial uncertainty reduces gradually by working with the child and building up positive experiences. Time and communication are of crucial importance in this process.

- ***You discover commonalities between a child with a disability and his/her peers.***

Teachers discover that the child has abilities too. There are not only the difficulties which determine who the child is. Teachers indicate that the visible limitations originally give them much concern.

In their stories teachers make comparisons with peers in certain situations. They cannot compare performances in class, but recognise other things that are familiar from the non-disabled peers. Wouter sees puberty with all his pupils:

"Of course there are tears, but that applies to each adolescent. Everyone is going to his secondary education with good days and more bad days." (Wouter, teacher of Nizrien, first grade of secondary school)

The teachers do not want to make the child more special than necessary. He/she is trying to do as 'normal' as possible.

"Wiske knows that she is different, but actually I try to make no distinctions. She has to go with the flow. She and her parents agree on that." (Tineke, teacher of Wiske, first year of secondary school)

- ***It's about a personal search process but you are not alone.***

Teachers find it very important to have their unique and personal searching in the process with the child (and the other children of the class). Luc tells about his learning process with Yani:

"The team compiled an individual educational plan for Yani. I also had my personal expectations, which I have changed as the school year progressed. I knew the action plan, I knew what had to happen and the rest was more intuitive. Sometimes it totally failed, but we learnt

from our mistakes. We could always try again." (Luc, teacher of Yani, third grade of primary school)

From the stories, it emerges that teachers like searching and experimenting in their class. So, they got the chance to really become the teacher of a child with a disability. At the same time teachers do not want to stand alone, they count on support of other people: a listening ear and a helping hand.

"I was allowed to ask every question I had. I wanted also to have my own search. That is successful but if there was a problem, I always knew where I could turn for help." (Jonny, teacher of Jerom, second year of primary school)

The presence of a safe fall back together with enough space for own initiative is suggested by many teachers as the 'ideal' combination.

Who they fall back on depends on the specific situation and this can vary. Teachers nominate a number of people who can support them with their questions, fears and doubts. Teachers talk about following aid figures: the principal who is behind the teacher, the parents who are very closely involved with their child and share personal information with the teacher, the support workers that can inform teachers about necessary adaptations, former teachers with their experiences with this child, therapists (physiotherapist, speech therapist, etc.) with expertise in a number of concrete points, and peers who know the child well. This support helps to confirm and to motivate, uncertainties can quietly be reduced and make place for new ones.

4.2.3. Participation of children with disabilities within the classroom

Importance of child participation IN the group

The key question is how a child with a disability can participate in a regular classroom.

Teachers suggest from kindergarten to secondary education to just do the same thing as with other children. They try to let pupils with a disability

have the same experiences as their peers. It is very important to feel part of a group. Gust said:

"I did never shut Senne out. For example, walk in the woods. That is from 9 to 4 with a picnic in the forest and all sorts of activities, really specific nature-oriented. Then you are there with a wheelchair. I always take parents along for large excursions, now we had to be with 4 man to pull and to push. Senne always went with us. Physical Education, stage performances, these were always with Senne. We have never asked Senne to stay at home." (Gust, teacher of Senne, the fourth year of primary education)

For many children, there are many forms of participation possible. What is feasible for them according to their possibilities and limitations? Sanne, explains this:

"Certain issues Charlie does together with the class. Sometimes he does arithmetic exercises around the same issue, but with easier numbers. Especially for maths we come back to very basic things, because that is very hard for him. For geography, history, religion, listening and reading Charlie has the same goals as his peers. During spelling, he works with the computer and with word prediction; we limit the number of spelling difficulties and the amount of words." (Sanne, the teacher of Charlie, fourth grade of primary school)

The crucial question within inclusive education revolves around how and when the child is involved. This requires from a teacher a different way of thinking, but this does not mean that the teacher is doing other things. It is important that the child feels good and enjoys the class. Learning does not need to be at the same pace and in the same quantities as for other kids in the classroom. This is reassuring and reduces the pressure on the shoulders of the teacher.

A child learns already by just being present in the classroom. Children pick up things even if the content is too difficult for them. They also learn a lot by doing and imitating other kids.

"Caroline absorbs an enormous amount. Her mother tells that Caroline plays at home what I have said in the classroom. She also sees a lot of things from the other children. They tie their shoes: well, well, how do you do that?" (Antigone, teacher of Caroline, 5th and 6th grade of primary school)

Adaptations⁴

Talking about participation, this very often goes along with adaptations. Teachers give plenty of concrete examples how they see differentiation can be achieved within the class. It is possible to have children with very different capabilities in one class, but this requires often adaptations in one or more areas.

- *Adaptations within the space*

There are organisational adjustments needed, especially for children with motor impairments. We see that the accessibility of the classroom plays an important role. Schools can think pragmatically and find solutions with the resources available. With additional ramps and handrails many accessibility problems can be eliminated. Often there is also need for an adapted toilet or a space where it is possible to take care of the child.

Within the classroom there are other adjustments. The teacher thinks carefully about the place of the child in class, where the additional material will be stalled... It asks some searching and organizing of space.

The teacher brings the teaching closer to the child. Cathy has done this with Jana:

"I put myself in a central place and everyone who has questions can come. I'm sitting at a table close to Jana, so I can keep an eye and help if necessary." (Cathy, teacher of Jana, third grade of primary school)

- *Adaptation in what the teacher does*

Teachers have expectations towards the child with disabilities. It's about believing that every child can learn when a teacher invests. Society is rather over protective towards children with disabilities. There is no need to pity but offer opportunities, so that children can give the best of themselves. As teachers learn more about the child, they can better estimate what may be good for the child and what not.

⁴ Based on the scheme of adaptations from Janney, R. & Snell, M. (2000).

For each subject teachers have to adapt their expectations to the child with special needs. They are trying to look for opportunities. It is a quest; always adjust according to what you observe with the child and in the classroom. For teachers it is reassuring that the child with disabilities has not the same finish line as the other children in class.

"What is possible for Wiske and what do we expect from her? For cooking, I expect her to find everything in her kitchen. So we fill in the action plan then. It is a detective work. You delete and you see fit. If you find her standing still, you just let her. She does not need to reach the same goals to get her certificate. She has time." (Tineke, teacher of Wiske, first year of secondary school)

Each teacher will submit his/her own accents in what he/she expects of pupils. You see that this also translates to the child with extra care needs.

"I expect that children of the third grade between September and June get a firm shot in independence. I expect that from Yani, too. It began with her food. Yani had to say herself if she was eating at school or at home." (Luc, teacher of Yani, third grade of primary school)

Adaptations ask a flexible planning. Teachers realize that this is necessary for many children. The planning as you put it on paper should be adjusted regularly. Teachers report that during their preparation they take into account the involvement of the pupil. Teacher Sanne works intensively together with support workers in order to ensure that Charlie can participate:

"We have been puzzling for a long time. In what subjects can Charlie fully participate? What does he not do? If he does it, how does this happen? That results in sharing my schedule of all lessons with the assistants. They know then what I will give in class and what they need to adapt." (Sanne, teacher of Charlie, fourth year of primary school)

Teachers give a lot of attention to the active involvement of the child with disabilities. It is very important to address children directly and grab their attention, even just by saying their name. Even if there is a support worker in class, it is the teacher who puts the child to work and remains up to date on what the child is doing.

Teachers give concrete examples of how they differentiate and pay attention to the involvement of the child. It is important that the child gets the chance to work and is confirmed in what he/she can. It is necessary to give children more time.

Multiple teachers indicate that they use their didactic material in a different way. They ensure that it can go around in class instead of just demonstrating. Working with concrete material makes the instruction much more accessible to children with a disability.

At times when there is no additional support, the classmates can often give help in a meaningful way. Teachers work with a buddy system or in heterogeneous groups. Learning to work independently can also be important at those times.

And yet... the expectations are not always adapted. In certain areas a child is treated just like all other children. If silence is required, the child with a disability also has to respect that. If the child does something that is not allowed, he/she also has to know that the teacher does not like it. Teachers indicate it takes some time before they dare to ask this.

- *Adaptations for the child*

In primary and secondary education, we work with multiple commands. It can help to limit this to one question and engage the child on that. Teachers go back to the essence of the question.

You see that the demand for children is also limited by no extra work or home work after school. Sanne says:

"We give the questions of the test in advance. Charlie also has physiotherapy and speech therapy after school and we try to limit his work at home. This saves a lot of time in studying." (Sanne, teacher of Charlie, fourth year of primary school)

In implementation there may be adjustments. It is easier for students to work on a worksheet with a simple structure, without many frills or distractions.

"If you give her a sheet with all figure exercises on, she cannot begin to work. She does not know how. If you take a simple sheet with really big diamond, of 1 x 1 cm, and you write each digit of the exercise in one box, she sees the structure and can understand what is expected from her." (Wouter, teacher of Nizrien, first year of secondary school)

Instead of open questions with a lot of writing, teachers work with multiple choice questions. Certainly with children with severe

communication limitations, you see that this way of working helps to respond.

"Her exam runs parallel with the other students, but there are other questions. It is all multiple choice and with less questions. Multiple choice questions are not always easy, because I take automatically those things that look similar." (Caroline, teacher of Emma, first year of secondary school)

There are certain components in the curriculum that can be replaced by individual goals. A child needs to learn to work with a (speech) computer. A child needs to learn to drive with an electric wheelchair. Within the week schedule the teacher looks for the best moments when this can happen. When is it difficult for the child to participate in his/her group? When are there moments that the other kids in class are working independently?

The use of tools can give extra abilities to the child with a disability to get involved in the classroom.

The student receives an already completed course. So he/she is sure that everything is correct. The child can follow the lesson, his/her attention focusing on the content and highlight important things. It is not necessary to write at the same pace as the others. It can also help to put structure in the content of the lesson, this facilitates the study afterwards. It happens quite frequently in the secondary.

We see that many children use a computer for writing. Teachers find inspiration and useful computer material with colleagues from lower years. We also see a large number of children using software to read texts on the screen (such as Docreader, Sprint, Kurzweil). They get the same content offered, but don't need to read it themselves. The computer is also often used to summarize and visualize. These adaptations can be very handy for several children in class.

Within the pre-school education and in primary education, we see that children get a role in the circle to tell about themselves and their activities. They tell on the basis of concrete photos or prints. This also happens with Caroline:

"For a book round she uses a page with beta symbols. She talks about a book she has read together with her mother. Caroline puts a lot of preparation in this." (Antigone, teacher of Caroline, fifth – sixth year of primary school)

For some parts of subjects children can work with other learning methods. Teachers often start with the offer available in their class. If the child does not respond to this, teachers look for meaningful alternatives.

"Numbers are very difficult for Charlie. We found a method in special education that works with very small steps and very structured. We tried this with him for certain parts of maths" (Sanne, teacher of Charlie, fourth grade of primary school)

Teachers indicate that concrete tools such as blocks or abacus, a game with cognitive goals, the use of a pocket calculator... can ensure that the child is involved in the content but in his/her own way together with the group.

▪ ***What are 'good' adaptations?***

It is important to determine how the child with a disability responds to the adaptations. Teachers see this requires time and a learning process to find out what a child needs. What is a good adaptation for one child, does not necessarily work in the same way for another child. It is necessary to search and try again.

Sometimes a teacher realizes that certain things are simply too difficult and cannot be done. It is important that a teacher can be honest and talk to the child. Charlie in the classroom of teacher Sanne wanted to become a member of the school choir:

"Very painful, but we had to say 'no' because the school choir has a specific intent. A choir is not singing along in the classroom. A choir is really singing well, rehearsals, performances... Then we had to say: this is not possible, but Charlie must also learn to handle that." " (Sanne, teacher of Charlie, fourth grade of primary school)

Teachers usually tell that adaptations happen quite spontaneously and are most of all a question of differentiation, flexibility and creativity of the moment. Teachers do not have to do this alone; they can search together with colleagues, parents, support workers and itinerant teachers. Teachers want to know what adaptations are made and why. It

is important to be able to determine together what is necessary and put the practical implementation in the hands of support workers.

Teachers indicate that other children can also benefit the adaptations made for the child with a disability.

"When I had an autistic child, I was heavily escorted by a revalidation centre. I got a lot of explanation of those people. I learned that, at the beginning of the lesson, I had to say what we were going to do. For other children, it is also important that they have their structure." (Geert, principal of Jerom)

Individual line of learning

Children within inclusive education follow their own individual trajectory. They don't have the same goals as the other children in the classroom. There is a search for how their individual goals can keep in touch with what the other kids in the classroom are doing. Teachers are constantly looking for points of contact. In this light Antigone says:

"After the instructions everyone begins to work on their tasks. Caroline takes then her journal. There is a page with six assignments she has to do that day. The special educator prepares it. Caroline follows her planning sheet and does the six tasks. We always try to put in one task that has a link with what the other children are doing. When we work around the theme 'electricity', Caroline has a worksheet with all kinds of tools that need electricity or not." (Antigone, teacher of Caroline, 5th-6th year of primary school)

How individual learning should be shaped can differ from moment to moment. It hangs together with the possibilities of the child and with the possibilities teachers can create. This requires creativity and preparation from the teacher.

Teachers indicate that they see much more learning opportunities than just only the scholastic such as maths and language. There are many areas in which children may have objectives: social contact, finding one's way in the class, group work, etc. Cathy gives a very nice example about Jana:

"When Jana came here, I had to hold her hand for everything. She could not change her clothes when we went swimming without help. She was 9 years old and I had to help her. I had to do everything for her. And now, nothing in that respect, I have to do for her. She learned so much." (Cathy, teacher of Jana, third grade of primary school)

In secondary education, we see that within the learning material very functional choices are made: what is interesting for the pupils to learn? What is important for him/her in the long run? Eef articulates this for Hugo:

"My goal is that the students will not be bored and that they don't waste time. I also want to teach Hugo something he can use in later life. I will not say that he takes as much from my lessons as the other pupils, but still, e.g. typing - it is very good that Hugo learns to work with a computer. He will need that, just like his peers." (Eef, teacher of Hugo, third year in secondary school)

Evaluation of pupils

It is important for teachers to know that children are able to learn. They want to see a positive evolution in the abilities of the child. The child is not in class to just sit there. Teachers feel responsible for what the children learn, just as with other children. At the same time, teachers become aware that learning is less linear than they sometimes think or teaching manuals pretend.

Teachers evaluate their pupil with a disability by confirming what he/she does well and the progress he/she makes. Each step forward is progress. Teachers see that it often turns around small steps.

Individualized expectations and goals mean individual tests and evaluations. Children with disabilities can be questioned on what they have learned and what they have done in class. There is often a separate report program, so the digits of the child with a disability do not affect the performance of the other children, when the average scores are put on the evaluation.

Preparing for tests and exams is something teachers often do in consultation with support workers.

"My examination will be forwarded to her support worker. She adapts that test. Often she makes sure that Wiske does not have to write much. She also gets fewer questions. Then she sends the test back to me, I check and I take it with me to class." (Tineke, teacher of Wiske, first year of secondary school)

4.2.4. Social relationships

Teachers recognize that the presence of a child with a disability means a clear added value in the social field. For very small children up to students in secondary schools, the learning opportunities in the social field between pupils with and without disabilities are big. Classmates experience in everyday classroom that everyone is different. Pupils with and without limitations should take account of each other, to play together, to talk, to learn, to work... Respect is a word that teachers use quite often.

Teachers have fears about the social relationships at the start. How will the children deal with each other? How will the communication go? Will there be more bullying? What can a teacher do to stimulate the social contacts? Teachers tell with pride how much they enjoyed the togetherness of the children:

"I think [the students] learn to handle it and they learn in social terms especially to take someone else into account. I must say I was scared in the beginning but they have always done very well. Also on a trip, always there were one or several children looking for Oskar. The class kept an eye on him and said: 'Come on, Oskar, come with me.' and he went with them. I found that very pleasant." (Chris, teacher of Oskar, first year of primary school).

Teachers see the positive effects in terms of social relations reflected within the classroom climate. They often impose a direct link with the presence of a child with a disability. Teachers experience less hassle and less discussion. The group of students has something that you cannot find easily in another group. They take care of each other. Making mistakes is less considered as a negative experience.

Cooperating and helping each other is a topic that many teachers talk about. In several classes they work with a buddy system and see this as a learning process. Students are not forced to be the helpers.

In secondary education, social relationships also get extra attention. Teachers experience that all pupils during puberty are thrown back on themselves. This colorizes the contacts between pupils. Certainly in the vocational education you see that teachers within the classroom work

with the same strategies as in primary education: have conversations with the group, set up a buddy system, stress the importance of the group, let them work together in pairs or small groups, etc. Teachers are convinced of the positive aspects of inclusive education on the social relationships:

"Hugo is really accepted by the rest, we also have a buddy system, allowing them to help him. Hugo sits in a very difficult group and normally you would expect that he would be bullied. But that is not the case, they take care of him and they go along well with each other. I think this is positive for that group. They are also students who certainly can learn something for the future."
(Eef, teacher of Hugo, third grade of secondary school)

The presence of a child with a disability becomes a very 'ordinary' experience. The children usually sit together in class for a longer period. They know each other. The pupils are used to provide support to each other and this happens very naturally. The children have to learn to live with each other, all different in abilities and talents. Teachers tell how caring children can become and in this way are able to accentuate their own social qualities. Sanne sees this in the fourth grade:

"There are a number of children in the classroom of Charlie who are not always that strong, cognitively spoken, but we can clearly see: he/she will be brilliant in taking care of other people, I can see him/her in an early childhood centre or a residence for elderly people." (Sanne, teacher of Charlie, fourth grade of primary school)

Teachers make a contribution to the formation of strong social ties within the classroom. They indicate clearly that they confirm and stimulate positive contacts between children. Teachers are modelling through their way of interaction by showing how you can help the child and how they talk to the child. Teachers often experience how they can learn from their students in class in this area of social contact.

The presence of a child with a disability provides an opportunity to work around 'differences'. They make the subject open through classroom conversation, by inviting an adult with a disability, with a story about 'being different'... In daily conversations there are also ways to talk about the possibilities and difficulties of children. Teachers provide the child with a disability the chance to put his/her story on the table, just like the other children. If there is something 'special', they can give more explanation. Children realize that it is not just about the child with a disability, but also about the child that every Tuesday afternoon has to go

to the kidney dialysis, the child that is being teased, the boy who is only interested in other boys, the girl whose parents do no longer live under the same roof... Each child is in his/her way different.

The classroom is a rich breeding ground to practice how we can deal with each other in a respectful way. However, the learning profit goes much deeper than that: it is about standing up for each other, searching for appropriate solutions, talking with each other... Luc highlighted this very much in his class:

"I think there are more advantages than disadvantages. First and foremost, the advantages I find in the social area, are huge. Children learn how to deal with children with disabilities. They find that not weird. They realize who Yani is and they have to look for solutions if they want to play with her, e.g. Yani wants to play monopoly. How do we ensure that we can do it? They are quite resourceful. Also the communication with the communication book. They go to sit with Yani, they take the book and begin talking and gesticulating. I think these are all benefits, those are all things that come in, where you don't give specific lessons but you are creating a living environment where children can learn a lot." (Luc, teacher of Yani, third grade of primary school)

The effect of the strong social contacts is not only felt within the classroom. As teachers go out with their class, they also feel how other children/people are watching and how their class deals with that. They are noticing and responding to prejudice. Teachers see that wealth positive not only when the children are in their class, but also in long term. Caroline tells about Emma:

"Maybe now they do not realize it yet, but I think the social aspect is really an added value. Learning to be open and accepting to people who are different, is an opportunity they will not experience much in their lives.. Sooner or later, it is in their head and they will be able to use it. I am sure. I think that is really a surplus for them." (Caroline, teacher of Emma, first year of secondary school)

4.2.5. Communication and cooperation in team

Communication is a crucial component in the work of each classroom and the teacher is dealing with the contacts with pupils, parents and colleagues. Communication within the team around the child with a disability is more explicitly present. From pre-school to secondary

education, the communication to and from the teacher is essential to negotiate the practice in the inclusive classroom.

Who is part of the team?

The composition and development of a team is a unique process that takes shape with the people around the child with a disability. Typically, a team consists of the teacher, the parents, the support workers, the care coordinator and school principal. Sometimes therapists (speech therapist, physiotherapist, occupational therapist, etc.) and members for the guidance centre (Centrum voor Leerlingen Begeleiding) are also part of the team. The team is not the same as the school team, where all the teachers of the school are involved. It is important that someone takes the lead of the team and that people come together on a regular basis.

What does a team do?

A team has a flexible and dynamic package of tasks. They think about how the child can participate in the classroom, school, family life, activities with peers... The team can act as a platform for exchange of information, for searching solutions together, for enunciating questions... This means for many teachers huge support.

"Usually the questions come from me: I don't know what I should do, or I think this or that does not work. Everyone is trying to help if there is a question or a problem. Jerom lives also in periods. There are, periods when things succeed and then suddenly you get a relapse and nothing anymore. I have moments I think: 'Oh no, now he cannot do anymore, now we need to start all over again.' But the team is very supportive then: come on, full of good courage, we are going to do it." (Jonny, teacher of Jerom, second grade of primary school)

Teachers indicate that there are many informal contacts at the school gate, during playtime... These moments are valuable and enriching. In addition, a number of structural moments are planned with the various stakeholders around the table. There they can talk about the progress of the child and their cooperation. The frequency of team meetings varies.

The role of the teacher within the team

The teacher is a key figure within the whole team. He/she spends a lot of time with the pupil with a disability. From the daily classroom practice,

the teacher can use the team for consultation, exchange, ventilation... The teacher can best estimate when he/she needs advice, wishes support... Geert as principal considers this an important part within the pedagogical philosophy of the school:

"We are working on a project 'the teacher as central figure in care'. It is the teacher who has to observe his class and it is the teacher who has to ask for help. If you have a child with concerns in your class, you should certainly do so. You can go to the parents, to the rehabilitation, to the care coordinator... If you do not do this, you disable yourself." (Geert, principal of Jerom)

It can be very useful as a teacher to prepare such a team meeting. He/she can take a number of guiding questions or can start from specific themes that are important for this child in class. It makes sense to bring material from the child to make the points concrete. Luc tells about the team meetings of Yani:

"At a certain moment the question came: we have taken a number of steps in reading but how do we proceed? In the case of Yani this is incredibly difficult, because reading has to do with making sounds and hearing them and this is one of the things Yani cannot do. We had to look for another reading method, a different way of learning to read. Then the team is important: we know Yani and together we take responsibility." (Luc, teacher of Yani, third grade of primary school)

Communication between teachers

In addition to the team meeting, the exchange of experiences, questions and doubts with colleagues who have experience with the child is very valuable. Teachers see this communication as a very active help during the transition period for information and reassuring tips to take a smooth start in a new situation. During the school year, last year's teacher can always use his/her experience to provide meaningful suggestions.

Inclusion does not stop when you leave the classroom. It is a matter of the school. It is important that teachers who monitor during play time, lunch break, in the after-school care, etc. get a chance to know the child. Informal communication and exchange of information is important for every teacher.

Communication with the parents of the child

The parents together with the teacher are the cornerstones of the team and are indispensable to talk about their child. They can communicate

with the child like no other person. A teacher gets a lot of useful information and tips from their experience and expertise as a parent. The school year starts with an open conversation with the parents about their child and the expectations towards education. Jonny indicates that this is not only important for a child with a disability:

"In general I think [cooperation with parents] is important. It is a decision to put your child with a disability in regular education. Parents subscribe to inclusive education and know what they are dealing with. They can provide information about their child that you would not discover yourself. " (Jonny, teacher of Jerom, second grade of primary school)

The communication with parents can take place through various channels: the chat before or after the lessons, the school diary, a note, phone, mail, etc.

"I love to have sufficient contacts with all parents. I report a lot of things to them and I expect the same from them. With Senne, his dad comes in every morning. I am there and a lot of parents bring their child to my class. I also remain longer at school, so parents can come afterwards." (Gust, teacher of Senne, fourth year of primary school)

It is important to be open and honest in the communication with parents. This is a balancing act between be open about questions and concerns and also respect the choices of the parents

"At a certain moment we expressed as a school our concern about the developmental opportunities for Charlie. We feared that he did not have sufficient opportunities for his motor and communicative problems. It was a moment of tension between his parents and the school. The message was not: Charlie can no longer stay here. The message was: should he go to a school with more possibilities for physiotherapy and occupational therapy? Then the parents decided that it was important for them that Charlie felt well and he continued with this group as long as possible. We went along with them." (Sanne, teacher of Charlie, fourth grade in primary school)

At the same time parents often ask advice from teachers. It is an interaction where parents and teachers search as partners. Tineke stresses the importance of home contact. The teacher sees parents in a different way and they can talk freely in their familiar environment and without the pressure of time. The teacher learns to know the child in his/her most reliable environment.

"By seeing Wiske at home, you see how she is at home. I know now what she is doing after school. She eats something, then turns on the radio and dances for half an hour. I can also start conversations with her about her interests: dancing and shopping." (Tineke, teacher of Wiske, first grade of secondary school)

Communication with fellow students

A lot of teachers emphasize the importance of conversations with fellow students. This can be in the beginning of the school year, following a required adaptation or in preparation of a field trip. Caroline outlines quite nicely how in the beginning of the school year the speech therapist is invited in class to reflect on the communication of Emma and the implications on her participation and interaction with peers.

"The speech therapist came and they all have learned about bliss-symbols and the use of yes and no-answers. I thought that was good, pupils had no experience with that before." (Caroline, teacher of Emma, first year of secondary school)

Central in the interaction with fellow pupils is an emphasis on interdependency. We are dependent on each other for support. Every child sometimes needs help and the teacher wants children to practice this within the classroom. In interaction with the pupils, teacher can tackle stereotypes and prejudice towards disability, gender, race, religion... This requires recognizing the potential of all children.

"I have said in the beginning of the school: 'You all have something'. One can have difficulties to read, the other has divorced parents, another pupil has asthma, you all have something, so learn to live together. That can work out very well." (Tineke, teacher of Wiske, first year of secondary school)

Pupils have questions. It is no problem as long as they can be communicated in an open and respectful way. It is possible to talk about those questions, as shown in the following example:

"The only thing they say is: sometimes he gets easier tests. Hugo has often better points. He also studies for his tests and works very hard. I make them clear that Hugo will not receive a certificate." (Eef, teacher of Hugo, third year of secondary school)

4.3. Conclusions

In searching for a more inclusive way of thinking and practicing within education, we are looking for commonalities or patterns across kindergarten, primary and secondary education.

Believe that all students have something to offer

A lot of teachers indicate that their way of teaching does not change, but their way of looking at children with disabilities changes (Jordan, Kircaali-Iftar, & Diamond, 1993; Forlin, 1996; Avramidis, Bayliss, & Burden, 2000). They learn a lot more about the abilities of children, while they were previously mainly focused on their problems. This also has an influence on the representation and approach of the other children in class. Teachers manage to put a step further than the traditionally known labels. They are practicing in searching and dealing with a strength-weakness analysis and this opens doors in the learning process of children and the teacher (Giangreco, Dennis, Cloninger, Edelman, & Schattman, 1993). The concern of the teacher is no longer the (developmental) level of the pupil or the capacities of the child, but the chances to involve him/her in the classroom.

Teachers indicate that they had often little or no experience with people with disabilities. They don't know what they can expect and how they can best serve the child in question. Communication and expectations are important considerations. Teachers want to act in class as 'normal' as possible. In all situations, adaptations, facilities, support persons or aid tools are necessary. How can this be tailored to the child, the teacher and the classroom situation, has to be decided very pragmatically. Teachers don't want to be blinded by the individual problems of the child, but focus on the interaction between the child and his/her environment (Barton, 1997). That way the possibilities for participation of the child become much clearer (Ferguson & Baumgart, 1991; Janney & Snell, 2000).

Importance of a relational classroom

Many teachers emphasize the importance of a positive classroom climate. Children have to feel at ease and comfortable before they can come to learn. This is getting more attention when working with a child with a disability. It is the basic objective for the child herself, the teacher, the classmates, the support workers and the parents.

The teacher has a relationship with the child and finds out how the child feels and learns by teaching him/her. The expectation that each child

learns the same way is outdated. Building a relationship with a child is used as a working tool (Corbett, 2003). It asks an emotional involvement. The teacher shows an active commitment and is building up an affective relation with the child. A representation of potentialities is priceless. This goes back to a number of values that teachers find very important, and are doing every day in their classroom practice: equality, community and respect for diversity.

All teachers speak in a positive sense about the social relationships within inclusive education. They experience this as the great added value (Fisher & Meyer, 2002; Soodak, 2003). The child with a disability has a contribution in the class and is not there to fill the group. The classmates get opportunities to learn what it means to be different and how they can handle it. Teachers are aware of the interdependence in their group: everyone is dependent on the other sometimes. The teacher can learn from children and *vice versa*. The children learn a lot from each other.

Space for communication and collaboration

Communication proves to be crucial (Hunt, 2004). Teachers mention many formal and informal meetings. The search for how the child can participate in class, involves exchange of information and ideas. This is often new to a teacher (Thousand & Villa, 1992). The image of the teacher alone in his/her class with the pupils is still prevalent. In the stories we see teachers open their door to outside influences. Teachers dare to consult other people inside and outside the school. They cannot do it alone. Questions and problems can be viewed and resolved if they talk with other people.

In consultation and partnership it is necessary to be aware of the power differences between people. A parent is very often in the most vulnerable position. Teachers, principals, support workers and the guidance centre often meet in advance. Parents have often the feeling they can only come to agree with proposals. Consultation, however, happens in process and gradually takes form. The decisions are not fixed in advance. Dialogue asks for reciprocity and takes every contribution seriously. In the area of communication the teachers admit that they want additional training or coaching (Villa, Thousand, & Chapple, 1996).

Meetings are often moments where the teachers fall back on other people who know the child well. They get confirmation about what is okay and can talk about their questions, concerns and reservations. Team is the place where the individual educational plan is formed and they look together at the evolution of the child (Mortier et al, 2010). The cooperation is growing: by working together people learn to know each other and determine what they can expect from one another.

Partnership with parents is desirable and is paying off in educating the child (Falvey & Haney, 1989; Hunt, 2004). It is about a conversation in which the child is central. Parents know their child and have already quite a lot of experiences with that child. How are parents watching their child? What do they expect of their child? These are questions that are crucial in the dialogue and in the development of the classroom practice.

Teachers invest a lot in their relations with support workers. We get a double message. Support is necessary and contributes to facilitating inclusive education. At the same time teachers often feel controlled in the presence of another adult in the classroom. It is necessary to get to know and respect each other's role. Teachers need to exchange information with support workers to keep up with what the child is doing, what adaptations happen and how the student can remain engaged in the classroom group. Shared responsibility is a key word in that communication.

Inclusive education is a matter of the school

In every story we return to the moment the school receives the request to take in a child with a disability. Teachers indicate that the school has no strategy to deal with this request. Initially, the teachers look for what they can offer the child with a disability and what they need to get started (Carrington, 1999). Teachers have lots of questions and doubts. Once teachers start to work and the individual educational plan gets its form, the questions diminish. The commitment comes, however, not from one individual teacher, but from a team. Otherwise, the project of inclusive education risks to be an isolated situation within the school and is not embedded in the care policy.

It takes a lot of balancing

Teachers fall back on their basic skills as a teacher (O'Donoghue & Chalmers, 2000; Van Acker, Van Buynder, & Van de Putte, 2005). What they do with all children in class, is also useful for the child with a disability. Time is a crucial factor to discover and to trust their own competencies. Teachers experience a need for information and coaching while they are doing their job. There is no need for an additional training on inclusive education. Inclusion continues to look for balance, with ups and downs: every teacher indicates that there are times that things are going well and moments when you are pulling your hair out.

Teachers find a balance between giving extra care to one individual and reaching the standard curriculum with the rest of the group. This puts pressure on teachers, but can be partially removed by individual educational plans. Teachers learn to expect from children (instead of show compassion), to adapt their expectations and to work with individual learning styles. You divide the attention between an individual and the classroom. This often gives a teacher a feeling of inadequacy. A child with a disability asks more differentiation and flexibility in the classroom management.

Teachers find a balance between addressing the social skills and cognitive aspects in their teaching (Giangreco, 1997). The passing of knowledge and the search for how they can teach something to a child is an important part of the job. Will the child with a disability be able to learn something? Can the teacher teach something to the child? With these questions every child is recognized in the role of 'pupil' and succeeds to transcend the status of 'child with a disability'. Teachers can play a role in stimulating and supporting social interactions. Cooperative ways of working are handled more in the class for creating opportunities to learn from each other. Here teachers also can take responsibility beyond the classroom at play times, lunch, field trips, etc.

Teachers find a balance between experiment and count on support. Teachers want to find out on their own by trial and error. They become more conscious about what they are doing in class. The child is in his/her class and the teacher has to take responsibility for the inclusion

process. If there is a problem, it is important to know with whom and how the teacher can solve it. The teacher should be able to count on confirmation and support when he/she needs it. Teachers learn to indicate where they can use support (Idol, Nevin, & Paolucci-Whitcomb, 1994).

In each conclusion being a teacher means seriously working to understand purpose and meaning of education. That is constantly subject to change. A teacher is bearer of renewal. They must respond to change in a creative and responsible way. One of the great educators, who saw this, was Paulo Freire (1970). We educate children and young people in education with hope and love. We want to teach in a positive way and combat discrimination and exclusion. Inclusive education and dealing with diversity is not just a matter of education, but of the entire society. It delivers questions such as: what sort of society do we want? What do we expect from our children? What should they learn? In which organisation should they learn? etc. These are very difficult and complex questions with no clear and instant answers, only a lot of reflection and dialogue with all parties involved can help to find our way.

Name teacher	Class	School	Age of the child	Label of the child	Support
Sylvie	first year of kindergarden	Small school, rural area	Boy, 4 year	Cerebral palsy, severe communicative and motor disabilities	Special educator/ physiotherapist/ speech therapist/ student/ nurse to eat and toilet
Annelies	Second year of kindergarden	Small school, rural area	Girl, 5 year	Developmental delay	Special educator/ student/parent
Bert	Kindergarden (3 years)	Steiner-pedagogy - city	Girl: 6 years, Boy: 5 years	Girl: autism + cvi and motor problem Boy: severe motor problems	2 special educators
Ann	First year of primary school	Small school, rural area	Boy, 7 year	Motor problems	Special educator + direct budget
Chris	First year of primary school	City school	Boy, 7 year	Down Syndrome	Special educator/ student
Filip	First year of primary school	School in rural area, practice school for teacher training	Boy	Growing disorder	Special educator/ student
Jonny	Second year of primary school	Idem above	Idem above	Idem above	Idem above
Geert	Principal	Idem above	Idem above	Idem above	Idem above
Cathy	Third year of primary school	City school - Jenaplan	Girl, 12 year	Intellectual disability	Special educator/ speech therapist/ student
Luc	Third year of primary school	Small school	Girl, 8 year	Cerebral palsy, severe communicative and motor problems	Direct budget
Sanne	Fourth year of primary school	Small school, rural area	Boy, 11 years	Cerebral palsy, severe communicative and motor problems	Special educator / direct budget
Gust	Fourth year of primary school	Small school, rural area	Boy, 10 year	Spina bifida	special educator/ nurse for toilet
Antigone	Fifth and sixth year of primary school	Small Freinet school, rural area	Girl, 12 year	Down Syndrome	Special educator/ student

Tineke	First year of secondary school	Middle school in city	Girl, 13 year	Down Syndrome + severe visual problems	Special educator/ direct budget
Caroline	First year of secondary school	Big school in the city	Girl, 14 year	Cerebral palsy, severe communicative and motor problems	Direct budget + nurse for care
Wouter	First and secondary school	Small vocational school	Girl, 13 year	Cerebral Palsy, motor problems	Special educator/ direct budget
Eef	Third year of secondary school	Vocational school in the city	Boy, 14 year	Down Syndrome	Special educator/ student

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Chapter 5

Sofie and participation

"Het tastbare laat zich alleen door het ontastbare vormen.

De werkelijkheid laat zich door niets veranderen dan door de geest. Daar ben ik wel achter.

Om de dingen anders te maken hoef je ze niet aan te raken, je moet ze alleen anders zien.

Het is niets. Het licht moet er even op vallen, dat is alles, zoals op de gravure achter het glas. Ineens merk je hem op en je kunt nauwelijks nog geloven dat hij je daarvoor altijd was ontgaan.

Dat is het ongrijpbare kosmische proces.

Ik ken het.

Ik heb het ervaren.

Noem het liefde en ik ben een magiër"

(Een schitterend gebrek, Arthur Japin , 2003)



Rhizomes at Redpoint, Scotland

Abstract

This chapter focuses on Sofie and her participation through primary education. The aims of such qualitative research seek to generate both descriptive and procedural knowledge that can lead to greater understanding of individuals with disabilities, their families and those who work with them (Brantlinger et al., 2005). Some of the early qualitative research in segregated settings on students with significant disabilities offered rich understandings of their identities as contingent on contextual possibilities (Goode, 1995; Gleason, 1989). Extracting meaning from this work to affect practice in inclusive environments where students with severe disabilities are freely included with their non-disabled peers poses a genuine problem. We want to investigate the learning of a girl with significant disabilities within inclusive settings during her primary school period, thereby offering more tools for re-conceptualizing their participation, learning and development. The six years I worked with Sofie as a personal assistant were brought together through information from personal notes, diaries going from home to school, interviews, observations...

5.1. Introduction

A story is a narrative. It gives opportunities for individuals to have a voice. Detailed, deep life histories can provide a voice and break through the silence. Telling the stories, uncovering the phenomenon of disability, assists in revealing the rich lived experience of the world of people with a disability. I want to revisit – once more- the amazing journey we took with Sofie through primary school, a journey of love and loyalty, a journey that continues and evolves.

The stories are stories of time, place and home. The interpretivist paradigm allows the revelation of uncovering these experiences. Ferguson, Ferguson, & Taylor (1992, p. 7) explains: “The emphasis on created and intentional reality within interpretivism places an unavoidable focus on discovering the multiple perspectives of all the ‘players’ within the social setting. Phenomenology reveals the way people understand their existence in relation to their world. “Is this not the meaning of research: to question something by going back again and again to the things themselves until that which is put to question begins to reveal something of its essential nature?” (Van Manen, 1990, 43). I went digging in the diaries that went from home to school, the observations, the team reports, my personal notes, interviews, individual educational plans, film material in the first and third year. It embraced many different people, places and years. I dived into that immense amount of material and tried to make sense of it. I kept the structure of the school years to have some holdfast.

With this work, I want to look at potentialities in the way Agamben describes it. Potentiality is often understood as that which is opposed to actuality, not-yet actual. Agamben goes beyond this binary of actual/potential. Potentiality is an existence of the non-Being because to say that something has potential implies this potentiality exists but that, at the same time, it does not exist as an actual thing (Balskus, 2010). Together with Sofie, we were and are able to see darkness. For Agamben, this experience of darkness is the experience of potentiality in-itself (De la Durantaye, 2000). Rather than saying that we cannot see when we are in

the dark, that we merely only have the potential to see, what happens when darkness itself becomes the subject of our sight, when the 'actuality' of sight is in the darkness of potentiality? We have to realize that all potentiality is impotentiality." To be potential means: to be one's own lack, to be in relation to one's own incapacity. Beings that exist in the mode of potentiality are capable of their own impotentiality; only in this way do they become potential." (Agamben, 1999, p. 182). When we give everyone involved in this story the chance to start from his/her (im)potentiality, this offers a sea of chances and learning.

These experiences and this story influenced my way of thinking and working immensely. It took me many years before I could get back and try to make it explicit and visible what insights it gave me. I needed distance and time to be able to write about it. I want to take people into the lived experiences of Sofie, her parents, the teachers, the peers and support workers in order to show that inclusive education is not simple, it is complex reality with many stakeholders and interests. Going along and be actively involved for six years shows that inclusive education is like a wave. We cannot measure the level or degree of it, it comes and goes, up and down, with good moments and less good moments. These six years show how individuals and things are changing over time and in place.

5.2. First grade

The first of September means the start of a new school year. It is Sofie's first school day at school. She is in Master Wim's class. Sofie is a bit nervous but looking forward to it. It is an 'experiment' in which nobody knows what is (not) possible or where we will end up. Sofie is the bridge that makes the journey possible. At home she tells us what her expectations for the classroom are.

Hello,

My name is Sofie. I can't talk, but I can answer simple questions with a yes (nod) and a no (shake my head). I am slower than other children, so I need more time to answer a question (you can count to 10 in the meantime) or to do a task (e.g. give me a hand).

In the beginning I will look at things from a distance, because I am a little bit shy. But perhaps I do like to ask or say something myself. For that, I use my communication book and the front page tells you how to use the book. Be aware, if I point to a symbol this is always a complete word and the words aren't always in the correct order. Once you get to know me better, you will find out that I like to make jokes: say something crazy or say no with a smile by which I mean ... yes! But you'll probably have to teach me that this isn't always possible.

I like music, theatre, people who make funny faces and jokes.

Because my muscles are sometimes weak, it is hard for me to swallow so saliva comes out of my mouth. I don't like that at all. My mum put a bunch of scarfs in my bag. May I ask to get out a dry scarf every now and then?

I am a little bit scared and worried because everything is new to me too, but still I think it is going to be fun. (Sofie, 01.09. 1999)

Sofie tells me after the first day of school: "scared" and "fun". I asked if she needed something. "need" and "pencil". To the question of whether she needed anything else she answered yes, but it is not in the book. Ra ra ra. To the question of what she had to do in the classroom: "listen" and "look" (Rita, mother, 01.09. 1999)

Sofie was very enthusiastic when she and I looked together at all the things in her school bag. Especially her school diary and the homework paper got special attention. She also wanted to tell me things with her communication book: "give", "need", "class", "scissors", "tomorrow". Do you need a pair of scissors tomorrow in the classroom? Yes!!! (Rita, mother, 06.09. 1999)

Class is fun

To be part of class is fun. Sofie experiences this personally and enjoys it a lot.

Your daughter is in good shape this afternoon. She is pulling Umit's leg to get her coat off and pushing her under the table with her wheelchair, stretching her leg, pushing her foot against the table... so he won't get her under the table. She grabs Nergis by the hair and together they are wrestling to get loose. Next we dance to Doolittle Plop: I have Sofie in my arms, Aysel holds her legs and together we jump. Sofie sat on my lap during the story-telling and we tied Umit in the wheelchair together. When we started doing sums, Umit realised that he couldn't get the wheelchair under his table and get his calculating book. Sofie and I helped him a little bit... During the colouring class Sofie sat together with the master and that is always terribly funny. Every time the children asked to borrow a coloured pencil she answered like a good girl. She was sitting loose and the children put her upper body up before asking a question. Nergis checked whether it was a yes or a no and then they gave the pencil. (Elisabeth, assistant, 03.03.2000)

Sofie protests if she cannot be part. She doesn't want to be away from the group. This confirms strongly the choice to give Sofie a chance in a regular school. She really feels okay.

The first thing the teacher says is that Sofie cried yesterday afternoon, in a way he had never heard before. She had to go home but she had had such a good time, she didn't want to. (Elisabeth, assistant, 21.10. 1999)

Master Wim takes great care to give the class an inviting and homely atmosphere where children can come to rest and learn together. There is a lot of space to walk around and seek each other out. The teacher himself sits among the children all the time. It's all about creating space and time where everyone has the feeling that he/she is welcome, counts and can work cooperatively. The teacher shares responsibilities with the children in the class in a way that is appropriate to their age. This asks for openness and the possibility to be flexible towards each other.

This afternoon, the teacher has divided the children into three groups so they know which teacher will put on their skates. The list is ready. Umit: "And Sofie?" Teacher: "Sofie doesn't have to put on skates. But okay, I will put her on the list as well." So Sofie is in the master's group. (Elisabeth, assistant, 10.12. 1999)

On Friday afternoons they don't do much more work and the children get the space to do things with each other: Okan receives a caress from Sofie, Dilek is waving a piece of cloth, Alisher passes and gives a kiss, Sofie pulls Kerem by his jumper and Kerem answers: "Get off my body!" (Elisabeth, assistant, 11.02.2000)

A nice anecdote that shows once more that children imitate adults... It is Friday afternoon. There are no assistants in the class room. Then Master Wim sees Sofie lying with her head on the table. What is going on? Has the breast-piece got loose? "Sofie is loose?", Master Wim asks the buddy. "Yes, master, because she has been tied up all day and it is only for a little while." So the master waits curiously to see how long that little while will last. After about 20 minutes the buddy fixes Sofie up again. Just like the class assistants do... (Rita, mother, 31.03.2000)

How can Sofie participate in the class?

A lot of energy goes into looking for and thinking about ways for Sofie to participate. There is conversation between adults and with the children: How can Sofie be part of the activities and occupations of first grade?

A lot of children pose questions about how the skating is going work be next week. "Is she going to watch?" "Can we put skates underneath her wheelchair?" (Elisabeth, assistant, 08.12.1999)

To offer the coloured shapes as an example is good, but there are too many figures on the piece of paper. In order to put away some of the figures with a white paper sheet, we need 3 hands and 5 sheets. I suggest to glue on only 4 or 5 figures per sheet. To Sofie it was confusing. (Rita, mother, 19.01.2000)

We can't take for granted that Sofie can join the group everywhere. Regularly, Sofie needs 'champions' who counter uncertainties, are creative and look for solutions to assure she can take part. To participate requires hook and crook from Sofie and her environment. It is team-work between the persons involved.

Sports day takes place on Tuesday by bus. I went to the principal to hear what was going to happen with Sofie. She wondered whether it was a good idea to take Sofie along since 1st grade is going to go for a walk in the dunes. With clear body language I made clear that Sofie was coming anyhow. Once we're on the spot we'll see whether we can do the same thing or look for an alternative. You can't decide in advance that she can't come along. (Lena, assistant, 25.05.2000)

Just being present doesn't necessarily mean taking part and feeling involved. Sofie's style of communication creates very strong obstacles so participating is only possible with extra support. At the same time a class offers a lot of possibilities where Sofie, by being present, can participate in her own way. It just happens. People work out how Sofie can participate. Other children keep on showing new or different opportunities for activity. They start to experiment actively. There are a lot of informal learning possibilities in the conversations, subjects and interests of children.

Today, Kader has read a story about a hat to Sofie's tape recorder. The master gave her the assignment to listen to it three times. (...) While he was recording the book, all the other children had to be very quiet and do their math sums. The master used all kinds of gestures to explain what the children had to do. Everything was heavily exaggerated and Sofie had lots of fun. I think you can hear that on the tape. (Elisabeth, assistant, 15.02.2000)

During playtime, Sofie cleaned the blackboard together with Derya and Ekin. She cleaned the ruler with a sponge. The other two were cleaning and I asked if she wanted to help. Very convinced: yes! (Elisabeth, assistant, 18.02.2000)

Sofie's unruly body confronts us with questions about how she can do things. The motor aspect throws up barriers a lot of times. As a consequence the participation is less recognisable for other people. Sofie makes great efforts, often with little result.

She was able to go to Gertrude's place to play music and especially... play the piano. We still had to find out how to get Sofie in the right position at the piano but in any case it is an instrument that appeals strongly to her. (Rita, mother, 17.02.2000)

Homework. A new motor exercise has been added. After Sofie took the stylus and pulled off the cap, I put the stylus firmly back into one of Sofie's hand. She holds the stylus firmly!!! (in the past she wasn't able to do this for 5 min) and I move her arm. Like this she's got the feeling that she can do more than when I only held her arm. Because of this, her motivation to look at the words closely was twice as big. Indeed, with every correct answer she could colour. (Rita, mother, 05.06.2000)

The context factors have to fit. An environment with not too many people, little background noise and familiar faces makes it easier for Sofie to join in.

First Communion. A very attentive Sofie inside the church and a glittering Stephanie who was happy to see that Sofie had come along to celebrate. During the reception Sofie was more absent again and once we were outside the hall we received a lot of attention again. This strengthens my presumption that situations with a lot of humming and a lot of people are difficult for Sofie. Hearing? Attention problems? (Rita, mother, 05.06.2000)

Master Wim regularly puts Sofie at the heart of focus of attention. He steers class activities in her direction by getting her in front of the class, by putting her 'in charge' or by sitting at her big table and organising the class from there. Sofie reacts very strongly to this and does her best to meet the expectations. To the teacher, the other children and the support workers this confirms her desire to participate.

Sofie has spoken in front of the class with her communication device. The class was as quiet as a mouse and... they found it funny off course. Her drawing got hung up on the blackboard. She was proud. (Lena, assistant, 10.09. 1999)

The children showed in turns a word to her and Sofie had to answer whether the children had read the word correctly. For a while she was the teacher of the class. I ordered the children to deliberately misread some words. Still Sofie picked out the misread words without any problem. (Wim, teacher, 29.09. 1999)

The teacher is going to do some colouring. The children are working. In the meantime the teacher is sitting next to Sofie at her table. I make copies for her homework. Kerem helps me cut and paste. Sofie's hand is lying on the teacher, in his lap or on his hand. (Elisabeth, assistant, 19.11.1999)

Sofie wants to participate and shows a great desire to be involved. At the same time she has to conserve her energy. Everything takes more effort and she is tired more easily. One wants to support Sofie to join in and one expects her to use learning possibilities to a maximum but at the same time one of the most important parts of the job is to ensure that Sofie's pace is followed and her efforts respected.

Sofie was very fit this morning. By noon, however, she was very tired. (Wim, teacher, 17.11.1999)

Indeed, not 100% fit, but yet 90% fit. Ekin was Sofie's buddy today and held Sofie's attention. She couldn't hang her head down for two seconds without Ekin saying: "Hey Sofie, look at this." And you know... it worked. She kept following the whole scene, although not always with her eyes. Her ears function as well! (Lena, assistant, 11.01.2000)

Learning in connection

Every day another child takes their place next to Sofie as her buddy. Children choose themselves when they want to try. They can do it for a whole day or for half a day. It becomes a must in the class: you are lucky if you MAY sit next to Sofie. There are expectations (empty her school bag, put her coat on, stay inside with her during bad weather...). Every child can work out for themselves what they are willing to try. Assistants and/or other children can help out where necessary. What every child does in their own way receives a lot of confirmation. You can see that children often imitate the things adult do.

Kerem was proud that he found himself a spot next to Sofie. He was still unsure about what to do but they did well together. He behaved as he should: not too rough but not too careful either.

Kerem said often: "Look, Miss Lena." He still needed lots of confirmation. The state of affairs: we're at buddy number 10. We keep on growing because soon Okan will have his first time. (Lena, assistant, 11.02.2000)

During playtime she was allowed to stay inside together with Umit and Okan. Umit wrote a word on the blackboard and asked Sofie what was written. 'Got' or 'Not'? First he gave both options and afterwards he split up the question. Sofie could earn little tokens that way. (Lena, assistant, 07.12.1999)

Invitations and chances to work together are offered to and by Sofie, the classmates, the teacher and the support workers over and over again. Working together implies learning together. Because of her complex motor and communication problems she always needs the presence of another person to participate and learn. At the same time other people get to know Sofie and learn to appreciate her. It is a very important instrument to look beyond her difficulties and to become intrigued by who Sofie really is and what she learns in the classroom. Learning is a process of connections between people who make up a classroom together.

We were doing maths together. I counted with Sofie's fingers. Then I gave her two options. I asked yes or no. Pretty soon Ekin was working with us. She looked at what Sofie and I were doing, counted along and did her assignment. Sofie had enough of it after 1 page. I put the sheet of paper in the holder before her and let Ekin do page 2. I went to work with other children. (Elisabeth, assistant, 12.11.1999)

When the teacher was sitting with her at the table, she kept putting her foot or leg on the table. "Sofie, no little feet on the table. You do this at home as well? I have never seen a child with her feet on the table." Sofie is laughing and struggling against the teacher when he tries to get her feet back under the table. (Elisabeth, assistant, 17.03.2000)

Working together is practicing over and over the game of give and take. Sofie is not always at the receiving end of support. By being constantly present in the classroom and paying attention, it is possible to create moments where Sofie can give. These moments make a big impression and show what she is capable of.

Language test - listening was taken. The children received a drawing and had to perform verbal tasks. 'Put a cross in the smallest tree.' Sofie did that one with me. Aysel was her buddy. There were a few tasks where Aysel didn't know what to do. She waited until Sofie had given the right answer and then copied neatly from Sofie. I could see Aysel thinking: I look at Sofie because she understands the master's language better. (Lena, assistant, 16.06.2000)

Working together occurs spontaneously as well as in an organized manner. A process requires space and time and you cannot force it. Being a buddy develops with every child at a different pace and in different proportions. Children start to sniff around and explore. They like to see what is possible, try it out for themselves and give it further shape. Sometimes this happens with hesitation, sometimes we deal with real natural talents.

From tomorrow on we start to work with a buddy calendar, That way the children can see when it is whose turn. Tomorrow it is Kader's turn. Aysel promised me solemnly that she'd keep an eye on things and train the others. (Lena, assistant, 30.11.1999)

For Galib being a buddy was completely new. He is open to it. Sofie seemed to like it. She put her hand on his arm and his shoulder. (Lena, assistant, 02.12.1999)

It is not just for the children without a disability that the learning opportunities are big. Sofie is confronted with questions as to what is (im)possible with social contacts. Not everything is good. She learns how we can deal with this in the first grade.

This afternoon Sofie really felt like teasing. She pulled Ekin by the hair and that must have really hurt because there were tears. Sofie received a punishment. The Big Mack made sure that they were friends again. Luckily! (Lena, assistant, 14.10. 1999)

Oh, oh, oh, our little Sofie isn't that silent little girl anymore that puts all her efforts into not being seen or heard. When Master Wim told her that, she could still laugh about it (on the wrong side of her mouth), but once at home ... deadly serious. "teacher", "Lena", angry" and "I". This morning she had to vomit, but maybe that's because she's nervous. (Rita, mother, 14.10. 1999)

Sofie was proud that she could give the drawing to Ekin and Ekin was very happy. You could see their friendship growing. (Lena, assistant, 15.10. 1999)

Aysel becomes a friend

There are a lot of opportunities for social contact and cooperation. For some children this evolves further into friendship. Between Aysel and Sofie something natural yet special grows. They are very much at ease in each other's company and they are very close. This becomes clear very soon.

Sofie shows her preference for certain children (Aysel, Nergis and Umit). She will make this more clear once her communication book is updated. (Wim, teacher, 10.09. 1999)

Aysel sees immediately that something's changed. She's got a new wheelchair. The teacher asks everybody to come and admire it. (Elisabeth, assistant, 07.11.1999)

Aysel sees Sofie's food tube for the first time. "Yuk, what's that? You can't show that." Lena explains that Sofie doesn't eat through her mouth, but through a little hole in her belly. (Elisabeth, assistant, 07.11.1999)

The day started with lots of crying, which was not easy for us to understand. Sofie told us she was hurting. I took her on my lap, comforted and hugged her. Aysel came to comfort her and promised to be her buddy today. (Lena, assistant, 16.11.1999)

The children like to sit in the wheelchair - during colouring - and play at being Sofie. Aysel also sat in the wheelchair and wanted the children to ask her questions. When she didn't reply immediately, the other children became impatient, and then Aysel: "I am thinking!" (Elisabeth, assistant, 21.01.2000)

The ladies (lead by Aysel) wanted to know whether Sofie was going to get married when she grew up. Sofie answered "yes". Then Aysel decides on Sofie's behalf, that the boy has to look like this: he mustn't spit and has to prepare the sandwiches for the little children. Incredible what's on that girl's mind! According to her it has to be somebody that can help Sofie to be a mum. (Lena, assistant, 04.04.2000)

Same and different - an issue in the classroom

Being together in a classroom is continuously balancing what feels common and is different. Throughout this 1st grade we are very often surprised at things Sofie does in the same way as her peers. There is more communality than we would think at first sight. Yet Sofie can't get started in the class without paying attention to the fact that she does things in a different way. Sofie is at once a part of the whole and exceptional. It is always a matter of searching for moments of encounter, but also respecting the differences.

Today things went fine with her little cup again (before and after lunch). One time it flew across the classroom because of a coughing-fit which caused laughter in the class. But after lunch, the little cup wasn't there for 5 minutes and she had to throw up. Result: food-tube out. This time it didn't all go as smoothly. Tissue bled a little bit, Sofie was very tense and counteracted a little bit. So we called the doctor at the medical centre, who was there fast. Sofie was tired afterwards (Lena, assistant, 10.09.1999)

Barabara came and Sofie did her utmost best. The stabiliser has been adjusted so we are going to start with it systematically next week. It will be twice a quarter hour in the classroom and once every half an hour in the gym. (Lena, assistant, 28.01.2000)

Today we practiced 'the double of'. The teacher pointed out somebody and then gave an exercise. Sofie also got one. Kader answered: "Is that correct, Sofie?" Sofie nodded yes. The children

waited until she answered. Again, another way to get her involved in class practice. (Elisabeth, assistant, 07.02.2000)

Aysel's and Kader's visit really was Sofie's highlight of the spring-break. I also remember Kader's remark during the puppet theatre, when she said indignantly to Lena: "Miss, these children are staring at Sofie. Why?" This is the most beautiful plea for inclusion: they don't see Sofie's disability anymore, they see Sofie! I hope Kader and Aysel enjoyed it as much as Sofie did. (Rita, mother, 12.03.2000)

Moments remain where the confrontation with her differences arise strongly. We are always showing openness in communication: we know what we are doing and we are open to questions.

Conversation with the teacher: he is worried about what Dilek's mother said. Dilek can't do any homework because there is a handicapped child in her class. It stays on her mind. Dilek has a lot of compassion and has to think about it a lot of time. She is a child who needs a lot of support herself, not really ready for school. Mother wants to give the impression that she's dealing with that, but she also wants to hide the fact that no reading or any work for school is done at home. Teacher will invite mother to come and have a look in the classroom and show her how things are done here and how Dilek behaves. We agree to pay extra attention to Dilek. Rita doesn't make a problem of this. She had expected that earlier on. She emphasises again that the assistance is there for the whole class. (Elisabeth, assistant, 17.10.1999)

Moments of belonging

When do we make connections? Where do we create interspaces of encounter that transcend similarities and differences?

Humour is a very important binding agent in the classroom. Sofie, Master Wim and the other children like to laugh and do it often. They find each other in things that they find funny and where they see that Sofie enjoys them as much and as strongly as the other children.

This morning Sofie made a whole lot of jokes. She laughed with everything that happened or was said. During language and maths lessons she paid attention. (...) Sofie was playful but gorgeous! (Lena, assistant, 10.09.1999)

Today, Sofie was the postman of the class. She had to stand (together with Mathieu) at the door (in the hallway). They had to ring (a real bell!) and wait until the teacher opened the door. Then she had to give her letters to the teacher. The letters were words that she spoke through her Big Mack. If the word was correct, she could give the letter. Otherwise the teacher threw the letter in the hallway. Great fun! (Lena, assistant, 05.10.1999)

The day started pleasantly in the gym. Sofie started out laughing from the moment we entered until the moment we came out. At the end, the children had to find a spot on the floor (far from

one another). Sofie was lying on her back. The lights went out. They had to be as quiet as a mouse but one person was laughing and screaming... Sofie! (Lena, assistant, 23.05.2000)

Giving responses and using body language play a vital role in the search for contact with each other. Communication through laughing, crying, moving... impresses. Sofie uses her varying muscle tension specifically to draw the attention and keep others close to her.

We sat in a circle (Sofie on my lap). One person went outside and one child in the circle swapped her shoes (left shoe to right foot). The person comes back in and starts her 'quest'. When it was Sofie's turn (with the swapped shoes) she was able remain serious until the person looked at her shoes... then she started to screech. (Lena, assistant, 24.11.1999)

At both lunchtime and also in the evening she pulled out her food tube. The same scenario over again: left hand 'glides' carefully from her table, rests for a while on the arm-rest and then slides towards the place where the conduct-pipe is in the food-tube. After that she makes eye-contact and 'plop', the food-tube is out! She knows very well that at that moment I can do nothing else but keep her hand away from the food-tube. When I give her a punishment (in the kitchen) I find her with the wheels in a puddle of milk. (Rita, mother, 17.02.2000)

Sofie has her own way of making connections through her body. She can do this very deliberately. Other adults and children see this as communication and they just let it happen or respond.

This afternoon there was always something that drew her attention, especially Master Wim! During the movie she was sitting next to him and she constantly tried to draw his attention with sounds, movements and by pulling his arm. (Elisabeth, assistant, 15.10.1999)

Derya is sitting next to Sofie. Sofie taps her on the back and touches her arm. (Elisabeth, assistant, 25.10.1999)

Sofie becomes Sofie in multiplicity

A first encounter with Sofie confronts people with gaps in their repertoire of meeting and making contact. It helps to get to know her, to know what she's doing, who is around her often... This provides subjects that you don't find out directly from her. At the same time you need time to acknowledge her yes/no-communication and body language.

I arrived at her house and Sofie sat at her place at the head of the table. She looked at me curiously and waited to see what I was going to do. It wasn't easy for me to estimate who I was dealing with. I was a bit reluctant to make contact with her. Her mother was also sitting at the table and I thought that I could only do silly things and I kept a distance. When the phone rang, I tried to put Sofie's slipper back on and she tried everything to make sure I didn't get her foot

back on the foot-rest. I kept on trying and suddenly I realised that this wiggling was no coincidence. Sofie laughed... (Elisabeth, assistant, 06.10.1999)

When time is spent with her and things are done together, Sofie gradually shows herself. A mystery opens up very slowly, but certain patterns repeat themselves, people start using certain adjectives more and more... Throughout this game of making explicit and interpreting who Sofie is, she exposes herself little by little.

Sofie is a 'phantom', she likes to tease.

During a class contest, Sofie was the teacher with her buddy Aysel. When she finished, she could choose the next Miss/Master. "Do you want to choose someone from the first row in the class?" "No!" "Would you like to choose someone from the second row in the classroom?" Yes! First Sofie looked who was sitting in that row. I saw her looking at her table too. Every child's name in the second row was mentioned. Nobody could step up because she had chosen herself. She also sits in the second row. That's one sly daughter of you've got there! (Lena, assistant, 23.12.1999)

Sofie likes to share.

Sofie's pegs are very popular. A whole lot of things are borrowed by other children. Sofie is happy to go along with this. (Elisabeth, assistant, 04.02.2000)

Sofie enjoys music and can be very focused at those times.

Sunday evening. A piece by Paganini on TV, performed by a Japanese violin virtuoso. And for Sofie the world stops existing; there is only herself and the violinist. She was watching it breathlessly. Every now and then she moved her head along with the music and for the rest, no coughing, no mucus. (Rita, mother, 07.02.2000)

Sofie is a good girl, still an important goal in 1st grade.

During dictation the teacher writes: Is Sofie a good girl? He says: "We don't know that for sure. That is a question." He asks Aysel and Ekin and receives a definite: yes! Kenan answer without being asked: yes. (Elisabeth, assistant, 18.02.2000)

Sofie is nervous when something new is about to happen.

He's only going to tell her this afternoon that they're going to the theatre, but Sofie is very nervous. (Elisabeth, assistant, 21.10.1999)

Sofie is proud.

Sofie was proud she could let her father hear how tomorrow she was going to say "thank you, madam". A well educated girl, that daughter of ours! (Rita, mother, 09.12.1999)

Sofie prefers that her parents don't get involved too much with the school.

Elisabeth, can you make it extra clear to Sofie that it is only for the meeting I am at school this afternoon, so I receive a more enthusiastic welcome? (Rita, mama, 10.12.1999)

Sofie has principles.

Because for Sofie blue is blue and she doesn't want to wear any other scarves at school, mother had to iron blue scarves this morning (yawn yawn). (Rita, mother, 16.05.2000)

Sofie likes hugging.

This morning Sofie really was a gorgeous child = laughing - working - paying attention when she was supposed to. She was also super-active during speech-therapy. We mainly worked at the four-keys-computer. That went very well again. Over lunch she was a real hug-child. (Lena, assistant, 02.03.2000)

Side-effects of participating in a regular classroom.

Initially Sofie doesn't do any homework. She concentrates and learns during the day. At home she can take it easy and a lot of time is spent on the therapy. Yet Sofie refuses to do in the classroom what other children did at home. In the classroom she wants to join in with what the others are doing. So we start giving her homework on Mondays and Fridays.

What a good girl! This morning she was very proud of her homework. The teacher drew a little sun on her sheet of paper and that made her beam. When the children show their homework, Sofie wants to do that as well. It is more real to Sofie that she does her homework at home and not in the morning in the classroom. I'll try to increase the homework and add explanations to it. You are doing a good job, Rita. If she is too tired or something gets in the way, no disaster. (Lena, assistant, 21.09.1999)

Homework is a subject in 1st grade. It is important for the children to show at home what they are doing in school and to learn to take responsibility. Being in order is something to work on and that is something where Master Wim uses Sofie as an example for the whole class.

The teacher is very angry with Galib, Kerem and Bojan because for the 3rd time this week they haven't done their homework. The class is very quiet and listens. The teacher says they'll have to go to the principal and that he will tell their mothers. Sofie starts, at first very softly but then

emphatically, making noises from her throat and waving her arms. The teacher reacts by pointing out how well she is doing her homework. (Elisabeth, assistant, 10.12.1999)

The parents are proud of the fact that Sofie does homework. It's something they can do together with her. It is new to them and it offers them a view of Sofie's abilities in reading and maths. Homework is an important means of communication between class and home about what Sofie is doing. Feedback from home comes to the school and the support workers explicit the way they handle things in the classroom in order to reach a more uniformal approach.

Doing homework can be lovely! I showed her a word and the letter 'm' and posed the question: is the letter 'm' in this word? She looked back and forth between the word and the letter very seriously before she finally gave her answer. The words that according to Sofie contain an 'm' we coloured together. This is an experience in itself too: she chooses the colour by herself very deliberately. So the colours of the last piece of homework are no coincidence. Of course I had to do the reading as well and you would almost think that she is following with her eyes. (Rita, mother, 16.12.1999)

It has been a while since we did some maths homework and it is striking that Sofie chooses the numbers a lot quicker and most of all a lot more clearly. She is a vigorous child indeed! (Rita, mother, 14.05.2000)

Sofie receives her results. She is evaluated on what she has learned in the class. This is a moment when we pause to see what Sofie has done over the past period of time. The worksheets are looked at again. They give a reflection of her abilities and further point that we have to work on. There is a lot of attention given to confirmation of her positive evolution.

Tomorrow Sofie gets her results and they are real results! Wim and I made some time to sum up her temporary goals and her results. Wow! (Lena, assistant, 14.10.1999)

And proud she was of her results, our little Sofie. And us too, of course. (Rita, mother, 17.10.1999)

The results are wonderful. For every class we set goals for Sofie (e.g. religious class: impersonating the story of Genesis). Sofie received grades for every course and didn't get a 10 for every course. There are also specific goals for Sofie such as keeping her head straight up and answering questions. At the end there is a personal commentary by the teacher: "You have been very good, so far, Sofie. You always pay a lot of attention in the classroom. You cooperate very well too. In addition you always do your homework. Very good. It is nice working with such a lovely pupil. I am happy you are in my class. You have already made lots of new friends. Try to work with the pupils that you do not like that much as well. Practice your reading regularly at home." (Elisabeth, assistant, 17.10.1999)

Cooperation in the team around Sofie

The adults that surround Sofie at home and in the classroom regularly come together. They exchange information on what Sofie is doing in class and in therapy. Everybody has their share from their own expertise and experience with Sofie. The way we work and the process we go through are more important than the results and what Sofie is doing. We reflect on our actions: what is going well? What is going less well? We keep a close eye on things.

I told Liesbeth there is 'team' on Thursday with Susan (logo). She's probably going to be there too, since she wants to come for an observation again. Tonight she's coming over to my place to discuss the last two weeks and the things Sofie has learned. We really get along very well, you can bet on that. (Lena, assistant, 18.10.1999)

Sofie's folder also contains the participation plans. Could you read them and give your comments? (Lena, assistant, 21.03.2000)

Within the cooperation we make a lot of space for mutual confirmation and motivation. The things we do well are put in the spotlight There is a positive undertone combined with a very strong us-feeling. The parents play a big role in steering the team. At every turn they try to avoid Sofie getting limited in her possibilities and opportunities.

Rita and Toon, Sofie is doing very well at school, you may be sure about that! (Lena, assistant, 24.11.99)

Thank you very much for your card. I was really surprised. It feels very nice to feel your support and appreciation for what we do. (Elisabeth, assistant, 22.12.1999)

You know, we simply understand each other very well. We're all on the same wave length and that makes miracles happen. Thank you. (Lena, assistant, 22.12.1999)

It is really unbelievable how you got to know Sofie in such a short period of time. Some people still didn't know her after two years but thought they did and figured they could justify a judgement. It will always be a mystery to me ... or you are extra-terrestrials after all. Let's stick to human miracles that can only happen when we look at somebody through positive eyes. (Rita, mother, 22.12.1999)

'Team' is a time to make new agreements that we try out in daily practice.

The teacher is going to tell Sofie when he expects her to do something else. (Team report, 23.10.1999)

Sitting down together with several people involved with Sofie helps questions to be asked and uncertainties to be identified and shared.

This afternoon I helped Sofie with her colouring. Yes = green bowl = continue. No = red bowl = stop. Sofie understood it rather quickly. A short while later I read the article about Sofie (and her style of communication) and noticed that they had worked with colours before. I started doubting then. Perhaps it is not such a good idea to work with those colours after all. (...) I'll let the idea rest for a while and wait for advice. (Wim, teacher, 10.09.1999)

We choose priorities and think about where we want to go. At the same time all decisions are very provisional. We can always make modifications according to what happens and what the needs are.

Sofie doesn't have to work if she doesn't want to. Social and communicative goals have priority. (team report, 05.03.2000)

The feeling that our process with Sofie raises a lot of questions and doubts with outsiders makes us stick together even more.

Let the inspector come now. All the paperwork has been done. I have been looking all morning for the originals of the exercises. The file contains every piece of homework in a separate folder (original + enlargement). This has been done with the tests as well. So we're ready. According to the teacher it is these kinds of things that the inspector wants to see. (Lena, assistant, 25.01.2000)

The principal asked if you wanted to become a member of the school council. The teacher thinks this is a very good sign. It means they are assuming that Sofie will be here till 6th grade. Don't feel obliged, but you will be able to take part in school decisions. (Elisabeth, assistant, 21.01.2000)

The team meetings have an informal character; eating and drinking, sitting cosily together. They require space and time.

Master Wim says that in the 15 minutes allotted for each parent meeting there's little he can say about Sofie. So he suggests you come at the end or make an appointment some other time. See what suits you best. (Elisabeth, assistant, 21.01.2000)

Learning in connection with each other goes for adults as well. Master Wim has two support workers and a speech therapist in his classroom. There is no recipe book. They don't know where they want to go, but they look for a way to make Sofie participate as actively as possible and organise the class activity with the different people involved. We start with the things Master Wim has to offer to the 20 children. The support workers make modifications for Sofie but they work in function of all the

children. It is clear to both Sofie and them that the teacher pulls the strings in his classroom.

In the big hall the teacher and I are initially worried that Sofie is frightened. She pulls a face as if the tears are about to come. I stay beside her, hold her hand and talk softly to her. Dilek comes and sits at the other side, because actually she's a little bit scared too. (Elisabeth, assistant, 01.12.1999)

When Master Wim is talking, you can't compete with that and Sofie just wants to ignore you. (Elisabeth, assistant, 21.01.2000)

The two support workers work very closely together. They give shape to the support within the class, a new concept for the school. They try to find their place without disturbing the teacher and the class activity. There is a very big drive in them, not only during the times they work in the classroom, but also outside of it. There is a lot of reflection on their work and on the participation of Sofie in class.

Together with Lena - They set goals for us. How can we make exercises for Sofie? How can we stimulate her interaction with the other children? How can we start interaction with a broader range of classmates? (Elisabeth, assistant, 18.10. 1999)

Yesterday we worked on the individual education plan. We selected all the goals for this year. Afterwards we were mentally 'empty'. Now we 'only' have to develop the topics for the participation plan. I've asked for extra information about maths because what we have now really isn't enough. (Lena, assistant, 03.02.2000)

Sofie as Rita and Toon's daughter

Rita and Toon show great involvement in Sofie's class activities. They share what they think about it. They join the search for what can be done and make their contribution at home.

On communication

I notice that the vocabulary of her communication book is getting too limited and is no longer focussed on her lived experiences. E.g. schoolbag, pen-case... Lena is going to deal with this. (Rita, mother, 06.10. 1999)

On Sofie's learning

I don't know what you did to our daughter but that book really put a spell on her. Tonight she really didn't know how to stop. I had to point out words and read them over and over again. She even answered my suggestion to stop with no. (Rita, mother, 01.12.1999)

On social contact

Rita also shows Elisabeth the drawings that Sofie got from her classmates. Umit is her friend. He likes to sit next to her. He does the colouring and lets her choose the colours she wants. (Elisabeth, assistant, 06.10. 1999)

They take full responsibility for the education and nursing of Sofie at home. This demands great effort.

Last night was quite chaotic with a lot of coughing-fits and a few false alarms. Result: a zombie mum and dad. Sofie remains a question mark. So far she seems in good shape. (Rita, mother, 20.12.1999)

After dinner, time for music. She couldn't have wished for a more beautiful end to the day. At undressing, it turned out she had a 39,3°C fever. She must have had it during the music but kept on smiling and cooperating. So we opted for a big hug from mum on the couch and hoping she's in good shape tomorrow. (Rita, mother, 05.06.2000)

Rita and Toon are very proud of what their daughter brings back home. They enjoy a lot of 'simple' things. There is feedback on what Sofie tells them at home and what they communicate with her about it.

Reading the New Year's Letters is an experience in itself. For the first time that she had something that was really her own, and she was beaming when she received the compliment that her friends know how to write in a beautiful way. (Rita, mother, 09.01.2000)

There are a lot of moments when they show their gratitude

Invitation:

With all the people who love Sofie...

With all the people who have worked hard on her inclusion programme the last couple of months...

With all the people who make inclusion possible... we would like to begin the year 2000 in an appropriate way. (Rita, mother, 14.02.2000)

*Sofie was proud when she was able to hand over her cake-box to mum for Mothers' Day. And beaming she was** while we listened to the tape. (Rita, mother, 14.05.2000)*

Sofie slept gorgeously with sweet dreams where she could enjoy the party some more. Those experiences alone make PAB and inclusive education worthwhile and meaningful. (Rita, mother, 25.05.2000)

They are the greatest pleaders of enforcing opportunities for their daughter. They prove themselves very stubborn in this matter.

What a great results our Sofie has! This has an extra dimension because this is the result of 'real' tests and not just some numbers put on paper. This is the first parent meeting in 6 years where we finally leave with a sense of satisfaction. It is the first parent meeting where we have discussed Sofie's qualities and not her shortcomings. It is also the first time that people believe that she has got qualities and that she's not some poor thing that lets herself be lived. It is the first time that she's not chained to that disability but can be who is she is: an 8 year old girl that wants to explore the world around her and moreover can be herself. In brief, it is the first time that they don't think in a defeatist way, but look together with us for solutions to problems. So much for this lecture but I had to get it off my chest. And as dessert... Liesbeth and Lena received a big compliment from the teacher too. Congratulations! (Rita, mother, 03.02.2000)

5.3. Second grade

End of holiday. There is already something which has been built, but it's always exciting to see how it's going to be. At home, Sofie is anxious to start again.

It's the evening before the new school year. This time not a scared and unsecure Sofie, but somebody who is very happy that she may be going back to school. Getting some sleep was more difficult but finally came at 9 p.m. I suppose that tonight a lot of children will have some trouble with their nerves. But one thing is for sure: she is ready for it. Good luck to the whole team. (Rita, mother, 31.08.2000)

Sofie explicitly makes contact with the new teacher. She looks for her attention, gives reactions and invites a relationship. She takes every opportunity the teacher offers to welcome her to the class. They get to know each other. This intensive introduction happens every year. Sofie starts the new school year very alert and awake, very 'present' in class.

Sofie didn't miss her start. This morning she was quite quiet. She observes really well. She keeps an eye on teacher Sanne and teacher Inna. This morning teacher Sanne drew a kitten for her. Teacher Inna sang this morning and made music. I think that they will win her sympathy. By playtime the teacher had already received a huge smile. (Elisabeth, assistant, 01.09.2000)

Sofie is really attentive when the teacher is speaking. The interaction between Sofie and the teacher increases. Sofie regularly gets her turn to answer questions. (Katrien, student, 14.09.2000)

Sofie becomes Sofie in all her multiplicity.

How do we get to know Sofie in this second year? There are things that we recognise as Sofie and how she shows herself in relations with other people. We unravel these layer by layer, like an onion. Things continue to grow and move.

Sofie likes to participate. She feels part of a whole and enjoys this. She is stubborn and doesn't easily let go.

We have done a run for charity. Sofie liked being with the class outside. After a while I thought it was getting too cold for her, but she wanted to stay. We got a warm blanket and tucked her in. Like this it worked. She had a lot of fun. (Sanne, teacher, 28.03.2001)

Sofie is interested in everything that goes on in the classroom. We discover through daily practice how her own interests, such as nature and shopping, grow. We try to respond to that.

Today Sofie is allowed to see the tadpoles. They move very quickly in their bowl. We need to pull the water back in time when Sofie coughs. She pays great attention to the fast tails. (Elisabeth, assistant, 21.04.2001)

During the afternoon we figured out what she wanted to do with Ilse and Lena. Very confident, she chooses shopping. She doesn't want to look at CDs, books, shorts, t-shirts or scarves. Ilse and Lena aren't allowed to buy anything (accompanied with a smile). (Elisabeth, assistant, 25.06.2001)

Making choices is not easy for Sofie, if only because of her communication. There are many opportunities for this learning process throughout the classroom. Sometimes it's hard for her to choose. Sometimes she has something in her head that is not offered as a choice. Sometimes the number of choices is too big. Sometimes she doesn't want to choose.

We listened to Christmas carols and looked in two toy books. Sofie hasn't chosen anything yet. One thing I know for sure, it is not going to be a doll. (Elisabeth, assistant, 27.11.2000)

After playtime we wrote wishes on a stone. First I had to sum up about 3000 things Sofie could wish. I always received 'no' as an answer. Finally I gave her 3 choices and she opted for: 'I wish you a pleasant street'. (Elisabeth, assistant, 19.12.2000)

Aysel chose a picture together with Sofie. First she sought out five and then Sofie was offered the choice. This was a hard one. After three attempts, she finally chose a very, very fine picture. (Elisabeth, assistant, 06.02.2001)

Sofie gets worried very rapidly. She wants clarification on what has to happen, when, how and with whom. Because she doesn't verbally intervene, we see either that people do not always fully inform her or that she wrongly interprets but isn't able to bring it to people's attention. This often leads to misunderstandings that affect her participation. She withdraws or is not entirely present.

After playtime it is teacher Chantal. Sofie isn't able to do arithmetic, so I do it with her. It's really not easy. I have to repeat the exercise several times before she wants to answer. During the afternoon I find out the reason: Sofie thought her regular teacher would never come back. After some explanation, she is happy again. (Ilse, assistant, 16.11.2000)

This evening I had a long talk with Sofie. (...) First I told her what Ilse wrote. She admitted that she hadn't wanted to answer or participate... I asked if she could express herself through the use of her communication book and explain why. Yes. First she selected the page with feelings and chose 'scared'. After that she chose 'school' and 'school results'. Then I asked her: "Sofie, are you afraid because Friday you will get your school results?" Yes. "Why are you afraid of your results? Can you tell me with your communication book?" No. Should I ask questions? Yes. Now it gets difficult to stay 100% objective. I made an attempt. It wasn't because she thought her results would be bad. It was because she hadn't attended classes for a while and didn't do all the tests. She thinks the teacher is going to be angry at her. (Rita, mother, 30.11.2000)

At times Sofie is aware of her limitations. In the second year we see this more clearly. She comes across these difficulties in her actions, in her communication and relationships within and outside the classroom. She wants more than she is able to do. Especially at home, she discusses the differences she feels from other children.

So we talked about her disabilities. I told her that her hands do not always want to do what her mind thinks, that there's a bump in her head. This is for instance why she cannot talk. But... she isn't stupid! Has anyone ever called you stupid? No. Well, you're not stupid, but everything is just more difficult and takes longer. Therefore, you can't do all the tests like other children and we don't expect you to do them. Everyone, also the teacher knows this and wishes only that you try your best. Then tears came... I comforted her by saying she is a very big girl who's trying hard. Even her peers know that. There came a smile on her face. (Rita, mother, 30.11.2000)

Sofie is not easily satisfied with her work. The demands she makes of herself are high.

Sofie found her own speech exercise not so good. (Elisabeth, assistant, 30.01.2001)

Affect as a force within the classroom

There are lots of occasions where Sofie 'affects' and 'is affected' in her relations within the second grade. We want to look in detail at how this happens and what it does to Sofie and the classmates, teachers and supporters around her. These meetings are intense and can be viewed both as product and as process. The moment itself impresses and affects relationships, but it does not stop there. Thinking in terms of 'affect' puts people constantly in motion. It is a huge source of learning with opportunities mostly unconsciously tapped within the classroom. The power of 'affect' works incredibly strongly in two directions, it can be positive and negative, and often we can only observe the effects.

Between Sofie and other children

During arithmetic Sofie will not cooperate. She keeps looking away. I ask: "Do you want to do arithmetic?" No. "Do you want to watch the teacher?" No. "You want to do arithmetic with Kader?" Yes. Kader as proud as a peacock, puts her book in the middle and starts to do exercises with Sofie. (Elisabeth, assistant, 11.09.2000)

Dilek and Derya remained with her. They draw on the blackboard. Derya asks Sofie: "What can I draw for you: a tree? A heart?" Each time Sofie says no. Derya doesn't dare to draw anything. I explain to her that Sofie is a little 'ghost', that she is teasing her. Derya wants to start and then the bell rings. I really feel sorry for her. (Ilse, assistant, 08.02.2001)

Playtime: There are a number of small children around Sofie. They say all sorts of things to her. After a while Beste comes up. She says something to the kids and pushes them all away from Sofie. In class she told me that the kids were saying dirty words because Sofie cannot speak, but she told them clearly: Sofie talks with a computer. (Ilse, assistant, 22.02.2001)

Between Sofie and the teacher of the class

This morning there was not much reaction from Sofie. She panicked while writing. She had a fever. I stayed with her in her quiet room for an hour. Then we went back together. Sofie started to look around. The teacher gave her some extra attention: holding her hand, concernedly asking how she felt... (Ilse, assistant, 29.09.2000)

We had a nice conversation about the fire department. The teacher tells the story of a child that got burned and has been in hospital already two years now. Sofie gives a frightened look. Teacher: "Two years is long, isn't it?" Sofie nods a forceful yes. Her complete attention really strikes me. She noticed everything. The teacher often supports her words with concrete material or tells a story around her lesson. This naturally attracts the attention of all the children. (Ilse, assistant, 19.04.2001)

Between Sofie and her parents

Again we found out a little more about our daughter. She has shown me through protests and yes/no questions that she no longer wants to wear bibs. She sees herself as too big (and right she is!). Therefore, there are twice as many scarves in the bag. I have made it clear that we don't have enough blue scarves. But that's no problem. Let's see if her shirt doesn't get too wet. (Rita, mother, 18.01.2001)

Between Sofie and her support workers

At noon we had a serious conversation. I told Sofie that I am a bit worried because she was so quiet. And... Sofie began to cry so hard I went pale. Apparently, she just doesn't feel good today. Only when I told her everyone has an off day once in a while, a smile appeared on her face through the tears. She had a lot of mucus that bothered her. (Lena, assistant, 19.01.2001)

Working together with other children

Every day Sofie has a new partner next to her, just like in first grade. There are a lot of variations in how they fulfil their role.

Today Tunc was Sofie's buddy. It was, I think, one of his first times. He already "dares" to sit next to Sofie, which is great. He is curious to see what Sofie does. Fortunately, there's also still Aysel, who sits very close to her. She regularly stops by to tickle Sofie, to laugh, to rub her back... (Elisabeth, assistant, 06.05.2001)

We see that some children bring along their knowledge and experiences from the first grade and put this to use, each in their own way. They share it with a new assistant, classmates, the teacher... They develop their range of support. And this does not only happen at school. For the first time, Sofie is invited to a birthday party.

The way the kids interact with Sofie is beautiful: they show me how the Big Mack works, they push Sofie, they sing songs for her... (Katrien, student, 06.09.2000)

Together with Beste and Aysel, Sofie did a crossword puzzle. Aysel spontaneously took my position. Using yes/no questions, they filled in the puzzle. Where to pick up shells? In the mountains? No! In the woods? No! On the beach? Yes! Sofie could also not resist teasing Aysel: You want to solve the exercise? No! Can I solve this exercise? No! Should Katrien solve the exercise? No! Her teasing smile emerged. (Katrien, student, 20.02.2001)

Other children are new and start their trip of discovery. The fear of the unknown is big. They need time and lots of opportunities to get to know Sofie. Children make their own pace and take the initiative in relation to Sofie. Copying and creatively trying out new things are important forms

of social learning. Within the classroom, the assistant keeps an eye on things and provides additional guidance.

Today it's Kerem's turn to be Sofie's buddy. At first he did not want to: he is afraid of the 'spitting'. I told him I would help him. Every time Sofie coughs, Kerem is alarmed and shifts his chair back. (...) At the end of the morning while reading a story, he leaves his chair and come to sit next to me. Perhaps because Sofie moves her arms? Was he afraid of that? (Katrien, student, 20.09.2000)

Durim was Sofie's buddy. It's amazing how enthusiastic the boy is. He takes a lot of personal initiative: fetching books, opening them on the correct page, putting messages into Big Mack, helping to grab the right colours... During playtime Sofie stayed inside with him. I was still sitting behind my desk, when he started to exercise with Sofie. He gave her two numbers and asked which one was the largest. Sofie answered with yes or no. Durim then put an <or> between the two numbers. Sofie was very amused. Later on he also sang songs into the Big Mack and Sofie had to push the button. Nice! (Elisabeth, assistant, 07.11.2000)

Buddy: Banu. You still have point out important things to her: wait for Sofie to answer, let Sofie choose... (Ilse, assistant, 29.04.2001)

Buddies can themselves make their support of Sofie as intensive as they want. They can even fulfil part of the task of the assistant. Sofie and her comfort help determine how far this can go. The assistant not only plays a role in helping Sofie, but also in working with the other children.

This afternoon we checked out Christmas trees and decorations in the city. Ekin, Derya, Beste and Galib took turns to push Sofie's wheelchair. I just had to jump in here and there for high steps and also to ensure that Sofie wasn't shaken about too much. (Elisabeth, assistant, 19.12.2000)

Erdem was Sofie's buddy. He really enjoys it. After reading we (Sofie, Erdem and I) did the exercises together. This way I had the opportunity to further explain some things, to awaken him from his daydreams... (Ilse, assistant, 20.04.2001)

I have made Tunc responsible for helping me when I put Sofie in the stabilizer. He can really identify himself in this role and is rightly proud. You can see his attitude to Sofie clearly changing. (Ilse, assistant, 13.06.2001)

Sofie is not always happy with a different partner every day. She makes a distinction between friendship and working together. It remains a very important medium for all children in the class to make contact without imposing anything on them.

Kerem was her buddy. This implies that a lot of my support goes out to Kerem. I really have to point out to him the various tasks he has as a buddy. During the break I had a conversation with

Sofie about "buddy" and "(dis)liking it". Sofie understands that everyone should get a chance, but she prefers Aysel, Kader and Beste. (Ilse, assistant, 22.03.2001)

In social relations within the classroom, the personal assistant is a facilitator in activities and interactions. She uses her own contacts with peers to make a link with Sofie. At the same time, the assistant always leaves space for the teacher and the children, keeping herself in the background.

I remain seated during playtime. Aysel takes her coat spontaneously and loosens all the straps . She helps put on the jacket. (Elisabeth, assistant, 10.11.2000)

We have done a drawing about our holiday. We drew the sea, sun and rocks. There were people allowed on the paper. Sofie had difficulties deciding what they wanted to draw. She had to laugh when I told Beste about the horse that almost ate Sofie or at least her wheelchair! (Elisabeth, assistant, 17.04.2001)

When the children were ready with their test, they were allowed to check the pictures. Sofie enjoyed the presence of everyone around her. The questions children asked about the photographs kept being directed at me. So I tried to direct all the conversation to Sofie and let her answer with yes/no. This succeeded, but for some it is hard to wait. (Ilse, assistant, 05.02.2001)

Children openly ask questions about Sofie. This happens out of curiosity and uncertainty. They want to know who Sofie is and what is wrong with her. They are also curious about her various aids.

This afternoon the children told stories about their holidays. Teacher Sanne asked Sofie questions. We responded together. There came a bunch of questions from the children: why doesn't Sofie talk? What is the use of the stabilizer?... We have explained the communication book and the cannula. Sofie thought it was okay to talk about it. (Elisabeth, assistant, 04.09.2000)

We had a class discussion about falling in love. First I asked Sofie if she had ever been in love. She said 'no'. The teacher gave everybody a turn and asked the same question to all children. Thus, she also asked Sofie. She clearly replied in the positive. Is it a boy? Yes. From the classroom? No. From the neighbourhood? No reply. From your street? No reply. You don't want to answer? Yes. (Elisabeth, assistant, 19.09.2000)

Sofie feels like swimming. (...) Of course the fact that everything is new and knowing that the whole class is watching you is quite exciting. The children all take a look. There are many questions coming up: What is that jacket? Does Sofie swim? Why do you hold Sofie so tightly? What especially struck them was the fact that Sofie has skinny legs. (Ilse, assistant, 22.04.2001)

In their honest questions, otherness is put into words and felt strongly. Simultaneously they often look at what they have in common, which is recognizable with reference to their own experiences. The classroom

offers many opportunities and topics for discussion with each other about abilities and differences.

For the rest, we did arithmetic exercises. For the last time it was about splitting ten. Banu I and Kerem took turns to give an exercise to Sofie. Kerem suddenly noticed that Sofie was doing the same exercises but a bit slower. This raises questions: Why is Sofie not going to a special school? Sofie can count, so she is smart? (Ilse, assistant, 03.05.2001)

Sofie's sweater is a bit up and Taner sees her diaper. He is clearly shocked. I explain why this is so. Taner: Actually, Sofie is only half disabled. Some things she is able to do and other things not, like going to the toilet. (Ilse, assistant, 31.05.2001)

Communication by and with Sofie

There are several ways Sofie interacts. In class Sofie mainly uses her gaze and yes (nodding) / no (shaking). This takes time and often the initiative to communicate directly with Sofie comes from the other person. It is not easy for Sofie to clarify what she really wants to say.

I have seen very clear 'yes'/'no' when Susan (speech therapist) was working with Sofie in the classroom. Now practice! (Ilse, assistant, 05.09.2000)

During arithmetic I give two possible answers and ask Sofie to look at the right one. This works very well. (Ilse, assistant, 20.10.2000)

Sofie has an extensive communication book (650 symbols). This allows her to determine the topic. By working with Bliss-symbols there is a higher abstraction possible than by working only with concrete symbols. It is not always easy to find your way in the book when you don't know the events of recent times very well. The communication book is only used in one-on-one situations. Sofie has high expectations of her speech computer. There is an intensive search for a suitable device whereby her communication book can be put on so that it is always available to Sofie. How to operate the voice computer produces a lot of problems.

This morning Susan (speech therapist) started to talk with Sofie's book. She first explained to the children how the book works and how important it is to follow Sofie's direction of gaze. She wants Sofie to talk about her speech computer. The first thing Sofie says: 'broken'. Perhaps she was referring to Felix (speech computer), which did not work. Furthermore, she says: 'it was not fun' and thought 'it was not interesting.' She cannot say how many computers she has tested so far. The children guess how many. Sofie has a lot of fun saying 'no'. She does not want to try the computer, but she wants to have one. Susan explains immediately that such a computer is very expensive. It is one of the first times her peers really clearly see Sofie talking with her book. (Elisabeth, assistant, 06.02.2001)

For the classroom, the speech therapist helps to develop a communication card. The most common words needed to participate in the classroom are on it. Once Sofie knows the card and can use it, it is stuck to her table board. This map plays an important role in rapid communication with Sofie.

The teacher asked if Sofie and I wanted to finish the listening exercise we started the day before. This was a very long story with lots of strange word combinations. I shortened the story and read it to Sofie. Still answers didn't come. I picked up Sofie's communication card. This went fairly smoothly. Result: 'I do not understand'. It was too hard. As regards the communication card, the colours are very visible, but with the numbers, I always ask for confirmation again. (Ilse, assistant, 08.03.2001)

The effectiveness of communication is low if you do not know which direction Sofie wants to go in. It is not easy to introduce nuances into a conversation.

I tell Sofie that I notice something is not OK. I ask if she wants to talk about it in class or during lunch. Sofie says she is in a bad mood. She's not happy. She has no pain. She has no quarrel with anyone in the class. She does not like school. This was all the information she gave me. Maybe we should wait and see what other signals she gives or what else she wants to tell us. (Ilse, assistant, 30.11.2000)

Communicating involves frequent frustration because Sofie cannot clearly explain what she wants to say. The complexity of her communication system doesn't make it easy.

She didn't want to, or could not say, how she got the green bracelet and the flashing light. She received those things, that's for sure. She grew impatient, and then came the frustration. But to the question 'From whom?' no answer came. To tell a story, the combination card and book are difficult to use. She doesn't sufficiently link the two and she even told me (with the card!): 'I do not understand'. (Rita, mother, 07.05.2001)

Sometimes Sofie does not want to answer. Does she have doubts? Doesn't she feel like it? Does she not understand it? Doesn't she want to? Is she suffering physical discomfort? Can't she concentrate? Can she hear the question properly? Doesn't she know the answer? This results in discomfiture which is not easy to deal with in a classroom. There are many possible interpretations, but often we just continue.

I do not know what's wrong with Sofie this morning. She doesn't react, not even to the other children. When I asked if she wanted arithmetic, she said 'yes'. We start and again Sofie doesn't

respond, not even to the other children. So it continued throughout the morning. (Ilse, assistant, 30.11.2000)

During the first part of the morning, the communication between me and Sofie wasn't very smooth. I could hardly figure out what Sofie wanted, not even with her book. I didn't feel good. (Katrien, student, 07.02.2001)

The annual school party

The school party is once a year. Each class prepares something to put on stage. It is an opportunity for teachers from other classes and parents to see Sofie in action. There is a search for how Sofie can participate, how her classmates can support her and what part she can play. Sofie is very nervous about the event.

This morning we immediately began practicing for the school party. We really had to come to an agreement about who pushes Sofie and who dances with her because there really was a fight. It's really starting to take shape. Sofie's old stabilizer is used to create a cow on wheels. (Ilse, assistant, 03.05.2001)

Durim really dances with Sofie. The teachers occasionally hold their breath for Sofie. She really enjoys it. (Ilse, assistant, 05.04.2001)

Sofie's dance partner is becoming increasingly enthusiastic. We agreed that he first asks Sofie for her hands. If he feels it is not quick enough, he takes them himself. For turning in circles, he always gives an arm. For dancing with the girls, Banu always arranges 'transport'. If she forgets, Aysel jumps in to help. (Elisabeth, assistant, 08.05.2001)

She really got through the school party very smoothly. The stress fell away and she slept like an angel. (Rita, mother, 13.05.2001)

Speech Exercising

For the first time the children get a speech exercise. Sofie gets space and time to work on this subject and to prepare. In this exercise she works intensively on her own goals within a class activity: communication, working with computer, talking in groups ... This happens in very close collaboration with the various people involved: the teacher, speech therapist, mother, the support workers and classmates.

The teacher has explained the speech exercise. The children have decided this morning that they will talk about toys. The teacher agreed that Sofie can choose her own topic. The teacher would like to see Sofie use her computer. I explained to the teacher we must see what is practicable. I have agreed that she will join the latter group. (Ilse, assistant, 18.01.2001)

Sofie wants to talk about the same topic as the other pupils: toys. She picks out the train that she can use herself with headrest and transformer. But it would be good to inquire again. (Rita, mother, 19.01.2001)

We had some time to talk about the speech exercise. Indeed Sofie chooses toys, but not the train. Puzzle? No. Doll? No. Bear? Yes, but which bear I wasn't able to find out. But we already know something more. (Lena, assistant, 19.01.2001)

Sofie wants to talk about the bear that she got from Aysel and about Simba. Tomorrow we'll try to figure out what she wants to say. Maybe Susan can put it all on the computer. (Rita, mother, 21.01.2001)

When Susan (speech therapist) was here, Sofie, along with Beste, worked on her speech. Sofie has already selected three things she wants to tell the children. It's not always easy to find the right things and she is really insecure about whether it will be good enough. Next week Susan will continue to help and Sofie will only have to use one button. Would you like to check the colour of the bear's eyes? Sofie wants to say something about it. (Elisabeth, assistant, 23.01.2001)

This morning Susan helps Sofie and Beste with the computer. The final preparations for the speech are made. Beste says what she wants to know more about the bear. Sofie decides that she only wants to talk about the white bear. They agree on operating the computer program: pushing with her head to scan and pushing the button to hear the computer voice. I can help her a little help with her head. Sofie is very tense. The teacher decides that the kids sit around her. Now she feels even more looked at. I take control over the head function with the mouse. Sofie hits her button. Once she gets started, it goes fairly easily. You can still feel that she is still very nervous. Beste helps by placing her hand near the button. Durim, Galib and Derya K. strongly encourage her: we want to hear it. The children think her last sentence is very funny. She has to repeat it several times. (Elisabeth, assistant, 30.01.2001)

Participating in class

The teacher gives Sofie lots of extra time. Participating is relational. You take your chance to make a contribution and teachers and peers give opportunities, wait and expect. Participating is a matter of seeing, letting see and being seen. The teacher is looking out for Sofie's involvement. There is more space for communication in the group.

The conversation in class turns around 'being sick'. Sofie also takes part in the conversation. Does your mum hug you if you are sick? Do you like this? The teacher took really her time to give Sofie the chance to answer. (Katrien, student, 20.09.2000)

The teacher dares more and more: she speaks regularly to Sofie during the lessons. She draws the other children's attention to what Sofie can do or is doing. "Look, Sofie is sitting up straight, she can already listen to the story." (Elisabeth, assistant, 25.09.2000)

Sofie has participated several times very actively in group conversation. She tells the teacher her room has no wallpaper and is not painted. The wall is white. She doesn't want it any other way. There can be posters on the wall. The teacher asks yes/no questions and waits patiently until Sofie answers. (Elisabeth, assistant, 15.01.2001)

Sofie always needs somebody else to be able to do something physically and communicative. She really depends on interpretations: what does she want to say? How is she doing? It's a process of trial and error, of trying and adjusting the whole time. While interpreting there is a willingness to share and to let other people help. We are always searching for confirmation from Sofie.

Then I was trying to get the straps of her new wheelchair right. I was pretty nervous. I think I strapped them right. Yet this seemed to me a very unfortunate position for her. It looks as if she has less space to move. Several times I asked Sofie if she was sitting comfortably. The answer was sometimes yes, sometimes no. During the break she wanted me to loosen the straps. (Ilse, assistant, 11.09.2000)

I'm so glad we have found the reason! I'm glad you had a long and serious conversation with Sofie. I talked it over with Sofie and yes, she is no longer afraid. This was also noticeable in her behaviour in class. She was responding again. (Ilse, assistant, 01.12.2000)

We were so excited today that we have done Monday's homework. Today's homework went so very smoothly, that of Monday was harder. It is not clear to me whether the exercise was too difficult or whether she did understand what to do. I scanned the closely packed letters with my finger. (Rita, mother, 08.02.2001)

Looking is a way of participating. For Sofie seeing things happen is sometimes as much fun as doing it herself. It requires less energy, especially if she feels unwell. Just looking gives Sofie an opportunity to take a rest. These moments are regularly admitted and built in for Sofie.

Sofie is still less active. She gives serious attention to what the teacher says and what happens in the classroom. She makes little effort to get started or to answer. (Elisabeth, assistant, 12.09.2000)

Sofie just wanted to look around all day. Answers came very slowly, she looked ill. But Sofie indicated that she was not ill, just tired. She did look at the rest of the class but we just couldn't bother her. Fortunately, Derya as buddy understood. Sofie could be who she wanted to be. Nothing is obligatory became the slogan of the day. (Lena, assistant, 19.01.2001)

Health plays an important role

The second year is characterized by many health problems. Sofie is physically never a hundred percent: stomach and intestinal complaints,

epilepsy, fevers, lung infections... They keep Sofie at home and affect her concentration and activity in the classroom.

We had a suspicion with all her sneezing: from Friday evening on we were left with our Sofie feeling ill. A lot of sneezing and high fever were the ingredients of her weekend. Friday night but for sure Saturday night the fever kept her awake. Occasionally an hour of sleep with long periods of crying and agitation. Sunday morning at 5 o'clock she finally fell asleep until 10... Sofie was a reborn person: laughing, making jokes... Only now she has shared the little creatures with her mother and it's my turn to walk around with a fever and runny nose. Can you call her dad if there is a problem? (Rita, mother, 18.09.2000)

Sofie looks really exhausted. I think something's in her body that does not belong there. She had diarrhoea. She threw up a bit and it had a greenish colour (!?) She was really pale. Could the hypothesis of hepatitis be true? (Ilse, assistant, 09.01.2001)

About 11 o'clock, we are about to start with the test. She grabs Derya, waves violently with her arms. She's very restless and makes a noise. She starts to cry. I take her to her quiet room. She has no fever. I take her on my lap until she becomes calm. While eating she's very much at ease. Still some milk is coming back together with thick mucus. This afternoon she feels more at ease. We keep it that way. Sofie says that the problem is her belly. (Elisabeth, assistant, 21.04.2001)

Sofie at home

Sofie has a very strong bond with her mother and father. They are always there. They keep a close eye on her. They are responsible for much physical care: in and out of bed, washing, feeding, medication administration... They depend on each other to get their family life together. Both parents have organized their lives around Sofie.

One more time to sleep and dad comes back. Now she really begins to miss her daddy. Jokes about dad are no longer made. (Rita, mother, 03.09.2000)

Sofie's parents want a full life for her. They dream and look forward into the future. They are a driving force within each (new) quest for communication and motor skills. At the same time her parents are gatekeepers for the choices made and sometimes they step on the brakes to slow things down. Is this feasible for Sofie? Is it still possible for those who work with Sofie?

Again another wonderful Adremo-experience. For all the attendees it is getting clearer than ever. This is it for Sofie. You should have seen this guy at work. What a drive! He gave us some interesting hints about how Sofie can use the headrest control. (Rita, mother, 25.10.2000)

Glad there are many ideas, but we must be realistic. Not everything can be achieved in the short term. If we try too much at once there's the danger that we won't do things thoroughly. Some things might get lost. Social interaction takes much time and energy and remains the priority. One day, unfortunately, is only 24 hours. (Rita, mother, 07.11.2000)

Each step is a step forward. Sofie's parents invest much of their time and energy in working with her, but they do get a lot out of it. Looking at what is in the glass, instead of what is not there, is liberating. They can stop proving that Sofie really can do things. They can stop fighting against defeatism or questioning her abilities. They share responsibility with other people who do not contradict them.

It is time for a little history. A little less than two years ago (April-July 1999) a "thorough" examination of Sofie led to some odd results.

- *Sofie refused to do anything with her hands. Everything she was offered, she threw on the ground systematically. When they showed her how to paint or to potter, she pointedly looked the other way.*
- *Sofie didn't use paper as a working tool, but as something to pick up, crumple and throw away. (this means stereotypical behaviour)*

So-called facts like these were used to illustrate that Sofie could not really be taught. We are two years on now and have two homework assignments with some handwork. In the story of Loeki you will find crumpled leaves. Oops... would she still?... No! The leaves are crumpled because Sofie wanted to pick them up herself. So every time I read a sentence (situation) and offered Sofie four drawings. It was a pleasure to see her grabbing her solution. I always asked her to confirm with a yes or no. Job number two was to colour the flag of India. The colours she could not choose, but the colouring she would do alone (!!). So, everything coloured outside the lines is done by Sofie and Sofie alone. In this way she gave the Indian flag her own accent. So she's not very into protocol I guess. So you see, maybe a long story just for that bit of colour. But sometimes we need to see things in a broader context to fully understand where she comes from. People who had dared to predict this, I declared them crazy. (Rita, mother, 22.02.2001)

Sofie's parents take a lot of the hassle on their own shoulders. They need to organize everything themselves: stabiliser, wheelchair, aids, her transport... People expect them to come up with a lot of initiatives and solutions. Nothing is done or decided without first checking with her parents. It is all about their daughter.

Frank, the orthopaedist, wants to change the wheelchair Monday morning at 8 o'clock. I really wanted to be stubborn and refuse because it is during school hours but then we would have had to wait until 28/11. This would not be fair to Sofie. So I agreed. But this means that Sofie will only be in school around 9.30. (Rita, mother, 16.11.2000)

The teacher also asked how we are going to deal with Wednesday morning. There is no need for an extra support worker the whole time, but she would like to know. From next week on they go

swimming on Wednesday morning. Maybe we have to get together and discuss the matter. (Elisabeth, assistant, 17.04.2001)

At the end of first grade Sofie and her parents moved to De Pinte, just outside Ghent. It is a vibrant residential neighbourhood, where neighbours and their children have close contact with each other. Sofie and her parents made several attempts to build a neighbourhood network for Sofie, but there are no structures or spontaneous arrangements like you have in a class. In leisure time contacts are a lot more superficial. They cover a much larger area than the classroom itself and are completely without obligation. We try to start very much from the common interests (like music), but contact never really comes spontaneously.

Together with Gertrude (music therapist) we went to play piano at the neighbours' house. Sofie was trying to impress Katrijn (neighbour girl). (Rita, mother, 14.03.2001)

Today, barbecue in neighbourhood and very bad weather. Fortunately, our Belgian army provided us with a big tent. After a few cups of sangria everybody got warmed up and very soon the temperature inside the tent increased. To remember for next year: take an assistant as bridge between Sofie and the other children. However, we notice that Sofie, although without support worker, reacts a lot more spontaneously to strangers than before. (Rita, mother, 17.06.2001)

5.4. Third grade

Just before the start... Sofie and people close to her are regularly confronted with the fact that society is not accessible. They often come across frustrating barriers in mobility between the places where Sofie dwells.

What do you do on your last day of vacation? First, they spend a few hours in the classroom putting everything ready for the new start and then there's just enough time to test the accessibility of public transport. Elisabeth is the most appropriate person for this job. From her experience she knows buses and trains like nobody else. She wants to try if Sofie can get from school to her house by public transport. They do not try the tram (deliberately?). In the stations the two of them will not be unnoticed. If Sofie has problems getting up and out of the train, they have to carry her. It will teach them that stepping in and out for less mobile people is very difficult. They get home unscathed, but Sofie was at one moment not so sure that they are heading "home"...

Why is this story on the first page of this diary? This is more than just an anecdote. Perhaps it reflects the attitude of the team: do not avoid any challenges, but rather face them. Always push

the limits for both Sofie and her surroundings, confront inadequacies with only one priority in mind: Sofie herself should be able to participate as much as possible. Everyone wants to belong. Assistants ? They come from Mars! (Rita, mother, 31.08.2001)

Uncertainty

We note through the dairies many moments of uncertainty with all who are involved. People sometimes do not know what to do. People sometimes do not know what to think. They ask these questions to each other in search for possible hypotheses and guidance.

There is uncertainty about the communication with Sofie. What does she want? How can you make contact with her? Sofie understands a lot, but it is not always clear for others when exactly Sofie understands or doesn't understand something.

All things that belong to a butcher are coloured red, what belongs to nature, is yellow. We are not sure whether Sofie really knows who is a butcher and what is his occupation. (Elisabeth, assistant, 27.09.2001)

Before we started the test it was clear that Sofie wanted to say something. (...) We came to 'Ayla' and 'thank you', but the connection between those words was not found. (Ilse , assistant, 26.01.2002)

"You left me here alone, I did not feel comfortable. Sofie looked at me and after a moment she let her head hang. I dared not to say anything. I was afraid I would not understand her." (Jana, student on visit, 12.03.2002)

There are reoccurring questions about her health, pain and physical discomfort. What is wrong with Sofie and how could we help her?

Sofie has not had a good night: she woke up several times and was already awoken at 6 o'clock. She claims she has pain somewhere, but where? Does she have some abdominal pain? Her two big toes are brightly red and inflamed since Wednesday. I try to make an appointment in the nearby health centre. (Rita, mother, 10.09.2001)

It is a never-ending search for what Sofie is capable of. What do we expect from her and what not? Where is she in terms of learning? Sofie's ability to learn shows large discrepancies. Sometimes she just takes the class like everyone else; sometimes she goes her own trail. What she shows, is that acquired?

Homework: Counting from 10 to 100 in tens passed without problem, she had trouble with the last two exercises. I asked if she understood it and she gave a hesitated yes, but I have my doubts. (Rita, mother, 20.09.2001)

Sofie has worked very hard. Now we also practice the tables till 20. It seems to work. (Chantal, teacher, 16.04.2002)

There is uncertainty at times when Sofie does not respond or confirm. We check whether the method we use is okay for her.

Hanna and Sofie work together. Hanna reads and describes a drawing. Sofie answers whether the drawing and the text fit to each other. The first time we got no response, the second time we did: tired? Too much pressure? Scattered? Too difficult? (Katrien, assistant, 04.12.2001)

After three words, there comes no reaction anymore. Sofie gives quite absent impression. It's probably a combination of underlying factors: heat, tired, not a simple exercise? (Katrien, assistant, 17.06.2002)

How can Sofie participate in the classroom? What can we require from her to get involved? Supporters often work together with the teacher to adapt activities. This is a process of search: what works? What is appropriate? What is possible?

Music is given by Miss Sien. She jumps in at noon to see how we could involve Sofie more. Can we try to beat rhythms with Sofie? Can she use a tambourine? What if we sing? Maybe something we can reflect on with Gertrude (music therapy)? (Elisabeth, assistant, 20.12.2001)

Miss Chantal is a magician

Chantal is a very involved teacher. She has sincere interest and beliefs in the abilities of Sofie. She is looking at herself, and searching what she can do as a teacher for Sofie. There is a strong bond growing between Sofie and her teacher.

At noon Sofie made a drawing with Banu. The teacher has put together with her some stars. The teacher asks her to close her hand around the pencil. She does not do this. The teacher 'enchants' her hand and closes it. Sofie gives a big smile and wants the teacher to do more magic. It always strikes me more on how the teacher very strictly guards the perspective and input of Sofie. It is quite natural. (Elisabeth, assistant, 01.03.2002)

I have a busy but fulfilling school year behind me. I got lots of fun experiences in my class. A very special 'thank you' to Sofie. She has taught me certain things to see, how to approach from a

different viewpoint, i.e. her position. I am very grateful for this rich experience! (Chantal, teacher, evaluation third grade)

She works with Sofie herself and searches for a way how Sofie could be involved. She creates opportunities within the possibilities and limitations of Sofie. She adapts tasks specifically to Sofie, rather than is found on what children in third grade are supposed to know.

The teacher continued the conversation. What would you do if you want to buy something and you have no money? The teacher gave several options:

To clean the street? No response.

To clean shoes? No.

To play clown on the street? Yes.

The teacher responded well to her last answer and Sofie laughed. (Katrien, assistant, 25.09.2001)

Sofie made this exercise with the teacher. In the meanwhile, the teacher corrected works of other children at her table. So, Sofie was offered time to give an answer. (Ilse, assistant, 15.11.2001)

Chantal thinks together with the support workers about what Sofie could learn in the classroom. The teacher often comes and watches what Sofie is doing. She is responsible for her learning and gives directions in priorities. She wants to give Sofie many opportunities what she considers viable for Sofie.

The teacher comes by to see how it goes; she knows what Sofie is doing and gives the next exercise. As I look at another group of children, the teacher shows Sofie that 1 inch is as big as her thumb nail. This serves as a reminder for the whole class. (Elisabeth, assistant, 13.09.2001)

We start with a test. First the teacher sets the class to work. Then it is Sofie's turn. The teacher takes some exercises from the test, and chooses the exercises we have already practiced: $\frac{1}{2}$ and $\frac{1}{4}$. Teacher: "We should give her tasks which she has not been sufficiently worked with. That makes no sense." (Elisabeth, assistant, 06.12.2001)

The teacher says to opt for more simple numbers. She points out to me that maybe Sofie needs her blocks also to see things clearly. (Elisabeth, assistant, 12.03.2002)

Miss Chantal says Sofie what to do, the assistant performs them with Sofie. There is a clear division of roles in a close collaboration. Chantal is open to the people who work with Sofie and is interacting a lot.

The teacher is incredible: she takes her role as teacher very seriously and really takes the lead in what Sofie does and learns. She says how Sofie participates and encourages the other children in their contact with Sofie as a pupil in the classroom. (Elisabeth, assistant, 13.09.2001)

Enclosed you will find the lesson planning for this week with a few exercises for Sofie. Maybe this is useful for the assistants. (Chantal, teacher, 18.09.2001)

The teacher paints with Sofie. When I return, the teacher told that Sofie has not worked well. Afterwards, I found the reason: the cannula was out. This makes a big impression on the teacher. I have given a lot of explanation. (Ilse, assistant, 16.11.2001)

Chantal has ideas about how Sofie can be involved.

The teacher gives ideas about the way offering exercises to Sofie. We now have a blackboard with chalk that we can use. (Katrien, assistant, 03.09.2001)

The children practice their tables. The teacher searches together with the supporters how we can involve Sofie. She's going to see Sanne (colleague of 2nd grade) if she has exercises that are easier. This is not the case. The teacher is doing the following proposal: Sofie grabs a number and we (the teacher or me) solve the exercise. (Ilse, assistant, 06.10.2001)

In the afternoon Sofie helps the teacher: she gave a sheet of paper to the teacher and the teacher than noted the points on the sheet. Sofie was proud that she could help the teacher! (Katrien, assistant, 12.03.2002)

Chantal experiments with the communication of Sofie. She asks her own yes-no questions.

The teacher was actively involved and even gave instructions to Sofie. It is very nice to see the interaction between those two. (Katrien, assistant, 06.09.2001)

The teacher shows great interest in Sofie's yes and no. She finds it somewhat difficult to see what is normal. She gives suggestions on what Sofie could draw. It must be something which you can dream of. Sofie opted for sea shells and fish. The teacher then let her choose the colours. (Elisabeth, assistant, 14.09.2001)

We started the day with a very fun language exercise. The teacher called five children who came to the blackboard. The teacher had one of the children in her thoughts and the children had to guess with yes / no questions. It was a training for the children in formulating good questions to Sofie. Sofie also said questions by using her Bliss symbols. Afterwards we did the same in small groups, but with school bags, rulers... Sofie and Ayla chose something and kept it in mind. Serhat, Ebru and Banu fired questions, Sofie and Ayla answered with yes or no. Sofie was very excited! (Katrien, assistant, 05.03.2002)

Miss Chantal explicitly addresses Sofie to participate in the classroom. She sets expectations for a contribution of Sofie. Simultaneously it ensures a context for adaptation, more time, many invitations...

Sofie is responsible for the order of the classroom next week. When the teacher says this, there is protest, especially from the new kids. Teacher: "Ah yes, Sofie needs and can work." They may hold the trash on her knees and throw it in the container. (Ilse, assistant, 07.09.2001)

The teacher gives the assignment to Sofie to search for the opposite word of 'day'. She continues classically. After a while, she asks if Sofie can answer. This is not the case. She waits patiently for the response of Sofie. (Ilse, assistant, 15.01.2002)

Within the curriculum of the third grade I look for connections with what Sofie has to do. I've learned not to underestimate her and to give her every chance just like the other children. For the rest Sofie does the same things as other children: she's joining school trips, she swims and gets homework. Like her classmates, she also has her turn in keeping classroom in order." (Chantal, teacher, 20.10.02)

There is so much space and attention from the teacher to affirm and encourage Sofie.

When Sofie was done, Ufuk and she demonstrated their exercise to the teacher. Sofie was complimented on her work. (Katrien, assistant, 17.09.2001)

Sofie has really worked hard and the teacher wrote down in bold a well-deserved 'Well done!' on her paper. (Katrien, assistant, 25.09.2001)

The beginning goes very fluently. You feel the effort it takes. The teacher sits with Ender. If Sofie is not responding and I have asked it already several times, the teacher intervenes: "What do you think, Sofie?" Sofie gives an answer and moves her head. (Elisabeth, assistant, 06.12.2001)

The teacher let other children benefit of the additional support and the adaptations of Sofie.

Miss Agnes comes along Chantal explained the benefits of Mind Express (communicative software) for her target group pupils. and was pointed by Miss Chantal to the benefits of Mind Express for her target group pupils. I think we will see her several times. It is good that there is more trust to learn from each other. (Elisabeth, assistant, 27.09.2001)

It is the first time that the tests from Sofie are also be used for Ender and Serhat. [These two children are several months in the classroom and are non-native Dutch speakers.] (Elisabeth, assistant, 01.02.2002)

Within the classroom there is an emphasis on working together. There is an extensive use of cooperative learning strategies. The teacher invests in solidarity with the children, between children, and between adults in the classroom.

After the playtime there was a "partner dictation". Each child was allowed to spell five words. Taner and Ufuk sat with Sofie in the group. First five words we dictated to Taner and Ufuk.

Then Taner and Ufuk dictated a word where we repeated the first letter of the word. Sofie had to indicate the first letter out of two choices. Sofie could indicate the letters a, s, b, g, d, e, k without problems. Taner applauded for her and Ufuk rubbed her back. (Katrien, assistant, 18.09.2001)

We work in groups, and study animals that live underground. We learn about rabbits. Sofie, Kader, Hanna and Durim form a group. Kader reads the small text and together we solve the two questions. All answers are then laid together. Sofie let the group hear her answers. (Katrien, assistant, 18.03.2002)

It is very important to me that I am not by myself; it is a team of people who work with Sofie and share the responsibility. The goals for Sofie are also formulated in meetings with all the stakeholders. I experience a lot of mutual openness in talking with the parents of Sofie and the assistants. The help of assistants and pupils is important not only to Sofie, but also to other pupils. The support works towards all children, but they can never define my role as teacher or take over. (Chantal, teacher, 20.10.2002)

Goals – and participation planning

What is offered to Sofie in the third grade? Where are we forwarding with her? We always reflect and make choices in the goals Sofie can work on in negotiation with each other. Participation is the starting point: Sofie is a pupil of the third grade and participates in the classroom, here and now.

The teacher has given her goals today. She took into account what Sofie is able at this moment and how we can continue. She also took into account what is being offered in the third grade and picked out meaningful things for Sofie. Perfect! It all seems so simple for her. (Elisabeth, assistant, 27.09.2001)

Sofie learns much cognitively. Similarly there are more explicit goals around communication and social objectives for Sofie than for other children. Finally there are individual goals that apply only to Sofie: the use of a voice computer, to operate the computer, and driving an electric wheelchair.

There are always new abilities discovered and gradually there are more defined priorities. What is relevant to create an optimal learning environment to and around Sofie? We also have to accept: we can always do more. It is not difficult to find meaningful goals for Sofie.

The individual educational plan (IEP) contains: communicative goals, socio-emotional goals, learning goals, learning strategies, and goals for home and leisure time. We try to review them halfway through the

school year and once at the end by way of evaluation. There are goals in the IEP of the teacher, the support workers, parents and therapists (2 physiotherapists and 2 speech therapists).

Maths

Sofie likes maths. She is motivated to learn.

I repeated the recognition of tens again. (...) Sofie also managed to answer the question: "Where are the six tens?". She showed the number 60. This I did not expect from Sofie. I was really surprised! Clever girl! (Katrien, assistant, 15.09.2001)

Sofie always indicated the correct answer. Super! (...) Teacher: "Sofie is a real calculator." (Katrien, assistant, 30.04.2002)

Term "maths" comprises different forms. This may include knowledge about numbers, calculations, mathematical questions, measurement, figures, money, clock reading...

We did exercises on + and - over the bridge. We made two questions out of one exercise: $60 + 35$ becomes $60 + 30 + 5$. Sofie looked or grabbed the answer on the eye gaze frame. (Katrien, assistant, 11.12.2001)

Before the leisure time, we worked with shapes. I drew a big circle, rectangle, square and triangle. I explained that we can recognize those forms. Sofie followed attentively. (Katrien, assistant, 25.02.2002)

There is still a continuous search without a clear vision. What Sofie shows, is what she is able of. What succeeds easily at one time, can fail the next time. It is difficult to view the development of Sofie as a linear progress. Building up step by step is very difficult: sometimes it remains a period of treading on the spot, sometimes she takes a big leap. Meanwhile, Sofie also works on other goals like fine motor skill, watching, working independently, focussing, keeping her head straight...

The teacher told Sofie to work at sums. I tried exercises till 100, with no bridge. The last two Sofie did independently. I added the task and the two possible answers to the eye gaze frame. Sofie read the task herself and then looked at one of the answers. I didn't read them to her, I just asked: have you read the question? Do you understand? Sofie looked at the answer with yes / no. The intention of the exercises was to see what Sofie still remembers from last year. The sums over the bridge and especially splitting was difficult. We are working further on this. (Katrien, assistant, 08.10.2001)

We started the morning with maths. Sofie clearly enjoyed. First we did an exercise on mathematical language. Example: 2 'H' more than 400 - What should we do? + or - ?. Sofie looked at her eye gaze frame to the calculation. This worked pretty well. Then we did exercises like $300 + 21$. Sofie solved all those precisely. It went smoothly! Recognizing the numbers till 1000 with two options were still difficult. (Katrien, assistant, 10.12.2001)

We learn much from detailed observation: what is Sofie doing? How does she do it? Where does she make mistakes? If we follow her well, we can experiment and add new challenges. That way we shape her individual program step by step.

Test of maths: this goes well. Sofie still makes mistakes in recognizing the numbers. Sofie points 612 instead of 621. According to the teacher, this is an error that often occurs. (Ilse, assistant, 26.01.2002)

When something new is offered to the other kids, this is a good time for Sofie to join. At the start the subject-matter of teaching is given at a calm pace. The most important components are explained thoroughly. The teacher often starts from experiences in the daily life of children and uses a lot of didactical material. This is a very useful moment in Sofie's participation with the group.

To put coordinates in a grid and to connect the points with each other. Together we looked at the coordinates and locations on the grid. I told her again what horizontal, vertical and curved lines are and let her experience this with her hand. We drew a line in the air. Afterwards we had to connect the points. Each time Sofie held the bar. (Katrien, assistant, 23.10.2001)

Recognition of fractions and make up a whole. I cut one sheet into four. Take 2 pieces and Sofie has to make it into a whole. (Ilse, assistant, 15.11.2001)

Long divisions are explained. Sofie follows well with the teacher, so she is familiar with the notation, the method. (Katrien, assistant, 04.06.2002)

Sometimes Sofie can work on another assignment than the other children in the classroom. She follows the classroom instruction along in the group. While working, the teacher can give her another exercise than the other children. Thus, for example, a lot of attention is spent to clock reading and recognizing Euros.

The children are working on time tables and division. The teacher asks if I want to work on Euros with Sofie. I explained what the Euro is, then, I showed her the different coins and bills. Next we played going to the store and buying something. Sofie shows the correct bill or coin out of two choices. She can differentiate the different notes and coins. (Katrien, assistant, 06.11.2001)

In the beginning of the lesson we follow along with the class. I'm looking with a buddy what a potential question can be. The buddy often speaks in the Big Mack. Sofie replies. Then the teacher gives another exercise, what number comes before and after? This goes very well with T and H. When the H are different, no problem. Sofie makes a mistake by the following exercise: 367: what is the number before? 376 or 366. I think she is changing T and H. (Ilse, assistant, 08.02.2002)

Some parts of maths were not offered to Sofie in previous years, such as times tables and divisions. This is now - one year later - build up little by little.

The teacher gave to Sofie 6 blocks. She must give half of the blocks to Merve. The same happens with 8 and 10 blocks. This worked incredibly well. Afterwards, Sofie must divide 8 blocks to Banu, Aysel, Ayla and herself. I was wondering if she was able to do that. Sofie gave the first block to Banu and Banu said she could give some blocks now to Aysel and Ayla. Banu guides Sofie. It works. Twelve blocks were successfully divided to 3 children, with some guidance. (Katrien, assistant, 27.11.2001)

Reading

On reading Marjolein, the speech therapist, is engaged to work with Sofie. There are individual, careful goals formulated. During one hour that Marjolein works in the classroom, Sofie works intensively on these goals and then she continues through the week. This makes space to learn to read systematically. The previous year there was always attention to this within the classroom. Now most children read and technical reading is not practised intensively anymore.

Yesterday we sat together with Marjolein (the speech therapist). It was nice to get together, just to sit and pass information. The following agreements are made concerning the reading method: letter recognition - this goes well, we complete the list - apply little words and auditory analysis and synthesis. (Ilse, assistant, 20.09.2001)

There is a lot of variation in the exercises offered to Sofie. Sofie is more motivated if a classmate is involved and/or if there is a connection with the exercises of the class.

This morning Marjolein and I have done a language and reading exercises with Sofie. Marjolein read the word in pieces (each letter) and Kader formed the word. Sofie had to listen and say whether it was the word she saw on the eye gaze frame. Kader then had to tell the opposite of the word. Sofie was not always attentive and needed to be encouraged very often. When we asked her if she wanted to rest, she said no. She wanted to work. (Katrien, assistant, 24.09.2001)

Together with Banu, Sofie fills in a recipe for making cake. Banu read the sentence and the word that should be filled in. We stuck two words on her eye gaze frame and Sofie showed the word we needed. We rehearse the words: flour, dough, method and mix. (Katrien, assistant, 07.01.2002)

We adjust the goals almost every week. The teacher and assistants keep a diary with comments about what they experienced in working with Sofie. They sometimes note exercises literally, so we can re-listen and revise what Sofie has learned. It becomes visible.

It is not easy to determine whether children who do not speak, read and how they do this. We try to check this by asking Sofie questions about what she read. Sofie finds this a great way of working and is very enthusiastic about it.

Sofie read a page from her book and said if she is ready (by pressing the Big Mack). Afterwards Marjolein asked a question about what Sofie had read and the possible answers were hanging on her eye gaze frame. Sofie indicated the answer and we went to the next page. We have read pages 6 and 10. What a result! I am still amazed! The result is in her folder. (Katrien, assistant, 29.05.2002)

Searching for a voice computer

Sofie tries various communication devices in the third grade. Susan (speech therapist) looks for a voice computer that uses the same principle as her communication book and makes Sofie more able to initiate in interaction with other people. There is always shortness of time to try the system. There are also many questions about the operation of the computer because of Sofie's motor impairments. This continues to be a relentless quest through elementary school and beyond.

Sofie herself has great expectations of a communication tool. She has seen the potential of it and desires very much to have her own voice computer.

Sofie wants to tell with her card. We come to 'to talk'. I already have a suspicion. Do you want to talk about the voice computer? Yes. This device of Joanna has quite impressed her. She finds it not necessary to first learn to drive with the Adremo. They can both be practised simultaneously. Maybe now it's the moment to try the Tellus? Sofie is in any case very motivated. (Elisabeth, assistant, 18.01.2002)

Susan is working further with Sofie on a communication program while expecting her voice computer. She tries to let Sofie communicate optimally with the resources that are already present. This is difficult and gives frustration.

We had a nice conversation. Sofie wants a voice computer and wants me to practice with her. The deal is: until there is no voice computer on the table of Sofie we practice with the class computer. We need to sit together and push forward a communication program, because for Sofie the computer must have a lot of words. I also promised to continue searching for a voice computer on her table. (Susan, speech therapist, 19.02.2002)

Humour – laughing and making jokes

Sofie uses humour to make contact with other people. Sofie laughs, this can be viewed in many ways, but it is usually associated with a clear response and it gets a positive connotation: Sofie likes it.

This afternoon we play to be under hypnosis. Beste reads a text with things we could do then. Sofie does not like to do things but she found it very funny when Beste and I did the things. Beste was, for example a cow that ate grass in the meadow. (Elisabeth, assistant, 27.09.2001)

Occasionally, the computer did not do what we wanted to our great annoyance. Sofie found that very pleasant. (Katrien, assistant, 03.12.2001)

There are many different types of laughter. If Sofie is howling out, then her body becomes very tensed and she is pushing herself upwards, her whole face smiles, teeth exposed, and there is much additional noise through her cannula. You see the pleasure and she pulls the others along.

In between we sing a song. I take Sofie's hands and we do the movements together. The teacher and children are looking at Sofie, it is screamingly funny for her. (Ilse, assistant, 20.09.2001)

Maths: Recognition of numbers up to 1000 - this is still difficult. I write the exercise down and Ender write two possible answers. Suddenly, I see him signing to Sofie the right answer. I react to this: "Ah, who is cheating here?" Sofie is howling out. This 's a real team! (Ilse, assistant, 13.12.2001)

Another commonly used smile means "I am only teasing". Sofie says yes or no, but then immediately begins to smile. You know she is pulling your leg.

During the break Sofie was a real teaser in our conversations! She did not want to know what I did yesterday; she did not want to go to her girlfriends... After each yes / no I got to see a jokes-smile! Sofie was in good shape! I noticed that her Ketnet (children channel) sticker on her

backpack was falling off. I asked her if she wanted to stick it somewhere else. Yes. Four possibilities: wheelchair - no. At the interior of her backpack - no. Communication book - no. Pink folder - yes. Sofie chose: vertically on the front seat. When it was stuck there, I asked her if she liked it like this. No + joke smile. (Elisabeth, assistant, 21.01.2002)

Sofie uses her humour to be naughty in the classroom. It attracts people. It's something people do not expect from Sofie. Sometimes she goes too far and must be whistled back.

When the drawing is done, Sofie must grab all the blocks and throw them into the box. The teacher is proud of her pupil and calls on Miss Sien and Miss Jenny to have a look. Sofie shines. But after a while Sofie grabs the blocks in the box and throw them through the class. She finds it terribly funny. The teacher is surprised. (Ilse, assistant, 21.09.2001)

Meanwhile, I want to get the Adremo (electric wheelchair) but after 5 minutes I am called. Sofie has pulled out the food tube. She laughs it off. Teacher and I show that we cannot tolerate this and we are disappointed. Sofie is impressed. (Ilse, assistant, 16.03.2002)

Sofie is a "ghost". She likes to tease. This is a constant element in the primary school. She "bothers" other children so she makes sure that they come to her. She amuses herself with it.

After leisure time Sofie wants to demonstrate her computer. She does this with Hanna. Many children come along for a look. Sofie is doing her very best. If Sofie steals the mouse and clearly enjoys this, Hanna is no longer able to help her with the scanning. (Elisabeth, assistant, 01.02.2002)

We started with maths. $H + H$, $H - H$, $HT - T$, a piece of cake! Serhat sees that it goes very fast. Sofie has even time for humour; she pulls the wrong card, and then shake 'no' if she swings the cards on the ground. Serhat always has to search them again. Big smile! (Elisabeth, assistant, 28.02.2002)

Laughter works for other children and adults affirmative: Sofie finds it okay. She's happy to be involved. We can continue like this.

During the leisure time Hanna comes to me to report that she is playing blind man with Sofie, "Sofie laughed out loudly, miss." (Elisabeth, assistant, 01.02.2002)

Sofie works a lot in third grade

Wow, Sofie has to work a lot in third grade. But she is very proud if we read out of her school diary what she accomplished this year. It's unbelievable to see the energy, activity and chances being given and how eager she is to take them! (Rita, mother, 17.09.2001)

The tempo of working in class is faster and Sofie has to work harder and longer. Her work speed also augments. We try to create more opportunities to work independently.

The teacher tells Sofie she worked very hard on her maths. She said: "I couldn't follow her pace to put new exercises on her eye gaze frame." (Elisabeth, assistant, 08.11.2011)

After playtime the pupils had to write words in their notebook. The teacher gave Sofie an assignment to make sums with hundreds. We started with 5 exercises, Sofie cooperated really enthusiastically. She wanted more and more exercises. In total we made 10 sums, it was incredible to see how busy she was. The last one she made on her own. Sofie read the question and the two possible answers in silence. Then she looked at what she thought was the correct answer. I did not talk at all. This is incredible, isn't it! Our Sofie! She deserves a big applause and some rest, I guess. (Katrien, assistant, 13.11.2001)

Sofie had no trouble with her homework. I am amazed with her speed of working in solving exercises. (Rita, mother, 03.12.2001)

There are clear expectations towards Sofie. It's not without engagement: the 'there are no obligations'-spirit disappears into the background. Sofie cannot just do whatever she likes; there are more strict agreements on what she is supposed to do in class.

Together with Marjolein Sofie has made exercise about comprehensive reading. Sofie reads the sentence that sticks to her eye gaze frame. Then she looks at one of the possible answers. It is difficult to motivate her. She did not feel like exercising, she is not motivated, but Marjolein insists that Sofie tries another exercise. She could curse Marjolein and shoot her with her eyes, but she persists and it worked out. (Katrien, assistant, 22.10.2001)

We continued with maths. It was difficult and Sofie was often distracted. The teacher insisted that we had to finish at least 5 exercises. We did them and then I let Sofie rest. (Katrien, assistant, 22.01.2002)

Sofie takes more control over things

Sofie is proud of her achievements, she would be glad to take initiative and show what she wants. Her choices are heard and respected as far as possible.

During language lesson, Marjolein worked with Sofie. She first wanted to tell something. She selected "teacher" and then looked toward her satchel.

You need something? Yes.

Should the teacher take it out? Yes.

The teacher took all kinds of stuff out of the satchel, but still it wasn't what she needed to find. Suddenly I got the picture and I asked if she wanted to show her results to Marjolein. Yes.

Sofie proudly showed her tests. Unbelievable, isn't it? (Katrien, assistant, 28.01.2002)

Tomorrow it is Sofie's birthday. This year more than the previous years she takes control. So... Sofie decided that each classmate receives a pen with a sticker from Disney. Sofie decided that her godfather could not bake a cake and Sofie decided that mini cakes could be baked. By the way, she has also actively helped to bake them. Enjoy! (Rita, mother, 06.05.2002)

Being seen

Sofie is seen. On the playground, children see Sofie busy and they have their idea about it.

Banu tells me that children on the playground all come to see Sofie. I explain that there are many new children and that they are curious because they are not familiar with Sofie. Last year Sofie was almost never on the playground. On the playground Sofie says little or is not very active. This may be a good point to work on this year. (Ilse, assistant, 06.09.2001)

During the afternoon I go and get a sandwich. There's a boy next to me I do not know.

He says: How's Sofie?

Me: Good.

He: Can she now drive her wheelchair?

Me: She needs a lot of practice and now she feels a bit sick.

He: What's wrong?

I try to explain that her stomach is not okay and she has a lot of pain.

He: I must be honest that I find the little hole (pointing to his neck) a bit nasty.

Me: That's really necessary. For Sofie herself it's not fun, huh?

He: No, but she has learned much in school?

It's my turn for a sandwich and I nod to him. (Elisabeth, assistant, 06.12.2001)

Dreams

Sofie wanted to say something. She selected on her communication card: I - drawing - clothes.

I asked if she wanted to say something more? Yes.

Can we do it with your communication book? No.

Can we do it with your communication card? No.

Mummy has to ask questions? Yes.

Then I asked her if "I - drawing - clothes" was referring to what she wanted to do in future. She replied affirmative. When I asked if it was a dream, a quick 'yes' followed.

Result: Sofie dreams about designing clothes. (Rita, mother, 15.04.2002)

5.5. Fourth grade

Preparation

Teacher Thomas only poses questions once Sofie is standing in front of his door.

As long as Sofie was in the first and second grade, it all was far away for me. I didn't really think about Sofie here at school and how things were going in the classroom. You don't do that with other pupils either. You're busy with those 20 or 25 who are in front of your nose that year and whom you're working with. Basically you're busy with your class. (Thomas, teacher, 11.02. 2003)

Thomas is not immediately in favour of the idea that Sofie will become one of his pupils. He has a lot of questions and doubts and he wants to inform himself thoroughly before committing himself to this. Through various channels of communication, he tries to prepare Sofie's arrival and he's clearly weighing the pros and cons.

The third-grade teacher is an important support for the teacher. What will the specific class activities be like if Sofie has joined the pupils? His concerns are mainly about Sofie's participation, his involvement as a teacher and his approach towards the support that is needed. He has many practical questions and doubts.

Just before Easter, I put everything on paper, in a very structured manner. Why would I like to have Sofie in my class? Why wasn't I into this idea? I discussed this with my colleague of the third grade. She had asked herself the same questions the year before. Chantal helped me out with a couple of things. She told me how she approached Sofie as a teacher and how Sofie took part in class activities. We also talked a lot about how exactly Sofie received support and how the teacher dealt with that. That way I was really able to talk about my doubts, and through a variety of practical examples I got an image of how she dealt with it. (Thomas, teacher, 11.02. 2003)

Thomas finds it necessary to see for himself how Sofie is as a person, how the interactions are going and how her relations with the other children are developing. Sofie's being different and certainly her way of communicating make him feel anxious and afraid. The first aspect/element that's necessary between a teacher and his pupil is a sense of connection.

I was very afraid of how Sofie would react: how could I make contact with Sofie? How could I see what she wanted to say? Would I be able to understand her and bond with her? The 3-day field trip that was organised for the third and fourth grade was very important to me. Sofie went along and I saw her doing things, I saw how the children and the adults around her dealt with her. Her fellow pupils showed me how they dealt with Sofie's presence and how they supported her. (Thomas, teacher, 11.02. 2003)

The principal helps the teacher to make a sound decision by discussing Sofie's situation thoroughly. . Thomas gets the time to form his own opinion. He has serious doubts about all the support workers and therapists that are coming into his classroom. In other words, he questions whether inclusion in education is the best option.

The principal asked me regularly: do you think you will manage? I discussed my fear about the guidance around Sofie: I was definitely not used to having so many people with me in the classroom. To me it really was a righteous question: why doesn't Sofie just go to a special school? My wife teaches in a school type-2, so I regularly come in touch with that world. The principal assumed that the parents had made another choice. Sofie's parents had chosen to let her go to a regular school, being fully aware of her limitations. . We had to respect that. (Thomas, teacher, 11.02. 2003)

Teacher Thomas exchanges information with Sofie's parents. He listens to their expectations and defines/establishes some clear conditions for himself, for Sofie and for the other children in his classroom.

While I was thinking whether or not I wanted to have Sofie in my classroom, I also explained what I didn't want. For example, I didn't want to nurse Sofie because that's not my job as a teacher. During lunch break, I just wanted to read my newspaper. For half an hour, I've got the time to myself, which is very important to me. I give myself one hundred percent during the lessons and afterwards I want some time for myself. I didn't want to do things differently either. I wanted to continue all the activities with my pupils the same way as I had done in previous years.. I have been very open towards Sofie's parents. All the parents have certain expectations towards a teacher. I decided to deal with these expectations just like I had done the previous years with all my pupils. Neither did I want to drop activities because of Sofie. We were going to swim, to see a theatre play, to ride a bus, and many other activities. I didn't want to take that away from my children. Some changes had to be made for Sofie, okay, but for the rest of the class it wouldn't be any different from any other year. (Thomas, teacher, 11.02. 2003)

During the last months that Sofie was in third grade, Thomas joined a few team meetings and the evaluation of third grade. This way, he is able to collect a lot of information about the specific approach and about the people he was going to meet.

I joined two meetings last year, which I think were important ones. After these meetings, I finally took the step: all right, I'll take up the challenge. . I will do this and that and last year

they did this and that. This worked out well, while that didn't work out so well. Okay, I start!
(Thomas, teacher, 27.06. 2003)

The beginning

At first, the relationship with teacher Thomas is somewhat tense. Everybody wonders what it's going to be like.

Finally we are there! Sofie has been looking forward to this moment for a while now. She is really ready for it.

Our first day of school has started. Not only Sofie is somewhat nervous, I myself can feel it too. I'm curious about what the day is going to bring. (Rita, mother, 02.09.2002)

Therapy for Sofie

Sofie works together with private therapists who have known her for a long time and have cooperated closely with her parents.

Sofie receives in classroom support from two speech therapists. Susan deals with Sofie's communication and finding the proper means for that. She works with Sofie individually at the computer, while the other children are in the computer room. Sofie's buddy can stay with her in the classroom. Using her book, Sofie can tell her buddy, what has happened in the classroom or at home. They can also work together on a school assignment. Marjolein joins the team as a second speech therapist in the language lessons. She adapts a book from Thomas's library and reads it together with Sofie. They also work on spelling. Sofie goes to physical therapist Dirk twice a week, after school. Another physical therapist, Barbara, comes to school twice a week, namely during physical education or during lunch break. Amelie is the occupational therapist who gives advice about the computer and the use of the aids in the classroom. Clearly, therapy is an important part in Sofie's daily activities.

It is a real puzzle at the start of every school year to fit all the therapies in the class scheme. Who can come when? Both the school and the therapists need to be flexible .

Swimming: this is a real problem. Barbara gives therapy in a town, about 10km from Ghent, from 8.30 until 9.30. So she can only arrive at the swimming pool at 10 o'clock. We hardly dare to ask it, but can somebody swap hours with teacher Thomas? If not, we urgently have to look for a solution with the assistants. (Rita, mother, 03.09.2002)

The therapy is fitted into the class schedule. The therapists, assistants, the teacher and the classmates all share the same space. If necessary, the therapists look for opportunities within the offer of the class. This approach is quite motivating for Sofie. The expertise of the therapists can be shared with all people involved.

Barbara introduces me to a few principles of physical therapy. Next week I'll try them out on my own. Sofie cooperates a lot better with Barbara during gym class than during individual therapy. (Katrien, assistant, 08.09.2002)

Susan wants to prepare the speech exercise and give her a voice by using the computer and asking yes/no-questions. (Elisabeth, assistant, 02.10.2002)

Swim classes: Barbara was surprised by Sofie's relaxed behaviour. This was a big improvement. and made it possible for us to let Sofie move without feeling tense. I received some tips that would definitely be useful. Sofie went with her head under water and got scared a little bit (Barbara too). (Ilse, assistant, 26.02.2003)

We can continue working with what has been developed during therapy. Like this we can really build further on what is important for Sofie and what is offered in the classroom. Assistants repeat and practice more within the classroom, whenever possible.

Elisabeth/Ilse: Suggestion by Marjolein: if you offer words with ei/ij/ou/au during language class and you explain these to Sofie, could you visualize them on one sheet of paper? This way we know which words have already been taught and we can use them during dictations. (Katrien, assistant, 02.12.2002)

The therapists continue to think about how Sofie can get involved in the class activities. They look for solutions to questions or problems that arise in daily practice. Moreover, they can make adaptations and help along to set goals for communication, motor development and computer use. Extra information finds its way to the classroom so the teacher, the assistants and the classmates learn how to estimate better what they expect from Sofie. The parents have a key role in bringing together all the information and the people involved.

Adjustment to the ruler: Amelie suggests attaching the grip to a wooden board first and trying out to what degree the grip is suited for Sofie's gripping. To be able to attach the grip, Amelie suggests filling up two openings at the bottom of the grip with a material and polishing it in order to have a smooth surface to glue on. Perhaps Toon can show a special talent tonight? (Katrien, assistant, 10.09.2002)

Teacher Thomas says that Barbara can also offer some advice on the gaze frame. Sofie can either look or take it away, so she doesn't have to do both. Looking is the best option. (Elisabeth, assistant, 18.09.2002)

I called Susan yesterday. She would like to develop a shopping card with Sofie. It would facilitate communication at lunch. She's thinking about a card with commonly used words such as play house and play shopkeeper. Perhaps we can already make a list? (Elisabeth, assistant, 02.10.2002)

Apparently, Sofie can't put her feet in the rests consciously. If she does manage it, it is likely to be a coincidence and she can't hold it for a long time. It also requires a lot of concentration. When her feet are released from the rests, they tend to be positioned outwards, next to the rests. Sofie cannot control this. When she smiles, we think that she does this consciously, whereas Dirk believes that she cannot or hardly control this smile because she realizes what happens. (Rita, mother, 17.10.2002)

During speech therapy, Sofie is made conscious of her own contribution. This goes a lot further than communication because we really tune towards what Sofie wants. It is about self-determination in a manner that is appropriate with her age.

Sofie asked me to make the content of the exercises more difficult. She asks something and we make it happen. So I added more difficult words, which still need to be explained to Sofie. Can you pay attention to this? This way she can broaden her vocabulary. (Marjolein, speech therapist, 14.10.2002)

Sofie doesn't know yet how she would like to dress on Friday. Perhaps you should take a look at this with Sofie and Susan? It shouldn't be too difficult! (Rita, mother) Meanwhile, Sofie has decided that she wants to dress up as a frog. (Katrien, assistant) Sofie 'lays down the law'. (Susan, speech therapist) (24.02.2002)

Therapy is heavy and requires a lot of effort.

We go home by car. Rita realizes that these moments also take away leisure time from Sofie. Perhaps we should take a look next year how we can fit this into the school hours? Now Sofie only arrives home at six, she eats, gets nursed and then she goes to bed. She should have some more spare time to do other things as well. (Elisabeth, assistant, 16.01.2003)

Use of the computer

Using the computer is very important to make Sofie more independent. More specifically, the computer creates communication opportunities in which Sofie can take initiative.

This diary is a good start of a communication programme for Sofie. How to use it? So far Sofie has used one key (yellow button). With this key, Sofie goes to the according symbol. When she

stops, you ask if it is this what she wants to say and then the assistant presses the button. (Katrien, assistant, 07.01.2003)

Finding out how to use the computer is exhausting. The difficulties in the motor aspects and finding out the correct use are an enormous challenge. The Adremo head-rest is used. There are experiments with using one key and using two keys. All therapists are involved because they each have a specific field of expertise.

Amelie and Susan came to join us after recreation time. They agreed to connect the Big Mack to the mouse pad. We switch on the Big Mack and connect the 'switch'-cable with the Big Mack. This way Sofie can scan. We're still dealing with it, because it isn't easy! (Katrien, assistant, 10.09.2002)

We still need to practice a lot to properly use the head-rest: it is not so easy for Sofie to keep her head nicely in the rests when she's pressing the Big Mack. Often the cursor goes further (because of her head movements) to the next square, so she hears something else than she intended. She has to watch the screen while doing the exercise. Still Sofie performed well. (Katrien, assistant, 11.03.2003)

Thursday afternoon around 2 p.m., Barbara will come to the classroom to see how and where the keys are placed best so Sofie can work on the computer. Make sure that Sofie doesn't cross her hands while using the buttons. (Katrien, assistant, 12.05.2003)

From now on, it is possible to practice on the computer during class activities. This practice session is held together with Susan, the buddy and the assistant. The other children are in the computer room at that time.

It is time for our one-hour session on the computer. We work on the numbers: we add up step by step and Susan or the buddy gives Sofie the answer. Coming up with the answer and going to it is still too difficult. Sofie pointed out the answer on the computer rather fluently. She did have to get used to working like this, but once we got started, we were on a roll. Nice! (Katrien, assistant, 28.01.2003)

Practicing always happens in cooperation with the buddy because it motivates Sofie. Sofie shows how her participation, certainly physically, goes hand in hand with the physical movements of her buddy almost all the time.

On the computer, we fill in the diary together. Aysel scans and Sofie selects. In the beginning it went smoothly, but afterwards it became more difficult for Sofie. Sofie started to get tired and it was also incredibly hot in the classroom. Then they cut the exercises: Aysel prepares it and Sofie pushes the handle so the cutting is done. Aysel takes the glue stick with Sofie's hand and they

glue together. Then Aysel hits Sofie's hand on the paper so it sticks together well. (Katrien, assistant, 01.10.2002)

What did the teacher learn from working with Sofie for a year?

Teacher Thomas sees that his approach to differentiate for Sofie also pays off with other children. The children's learning styles are much more diverse than he originally thought.

I think you learn to differentiate and to find solutions for children who learn in a different way. You learn to look for various opportunities. In the case of Sofie, you notice this fast: Sofie shows you immediately whether it is good. If not, you have to find another way. It is Sofie who shows me. This way of thinking is then extended/applied to other children in the class. You immediately see if the new learning style fits the pupil or not. If not, you should adopt another approach. . Clearly, Sofie makes you think about the other children's learning styles. (Thomas, teacher, 27.06.2003)

Thomas has come to realise that working with several people is necessary. He experiences the other support workers less and less as priers/people constantly looking over his shoulder. He manages to be himself in the classroom with or without them.

Teacher Thomas was very pleased. More and more he becomes the central figure. This morning I didn't even have to read Sofie's diary. He told me everything:

- *Secure Sofie, she can cough seriously and otherwise her head hurts.*
- *We continue with the tables of 3, 4, 5 after 20.*
- *Sofie gets tired more easily.*

He can better estimate what to expect, which is really nice! (Elisabeth, assistant, 15.05. 2003)

I learned to work with other people in my class. I must admit, sometimes I thought: 'be careful now'. But afterwards I thought 'whatever', I am not going to react differently than I would do otherwise. If I felt I had to respond, I did it. It is much easier to allow someone in your class. You have to, you cannot do it alone. (Thomas, teacher, 27.06. 2003)

Teacher Thomas takes a more flexible position towards the curriculum. He sticks less tightly to his schedule and is able to teach more in a way the pupils can handle it.

This year I have often adopted the following approach: when the pupils didn't understand something properly, I suggested trying something else instead of insisting on trying it over and over again. I realised that I could try again the next day. This is also how I work with Sofie. If she doesn't understand the table of 6, I suggest trying something else. This way, you take the child more into account instead of trying to complete the subject regardless of the pupils' needs and abilities. . In short, I have become much more flexible. (Thomas, teacher, 27.06. 2003)

Sofie's presence in the classroom has really improved/facilitated the social contacts between the other pupils. Thomas sees how children learn from each other in daily communication.

Aysel did maths exercises together with Sofie. First I wrote down some exercises, then Sofie and Aysel solved them together. It was heart-warming to see them collaborate. Afterwards, they went together to the teacher and asked him to correct the exercises. (Elisabeth, assistant, 13.11.2002)

This morning while I was entering the classroom, Daniel and Stefanie show me the red spots on Sofie's face. I explain that it's because of the cold. Halil wants me to do something about it. I have no cream on me, except a Labello lipstick. I rub it on her face. Miraculously it helps. I need to repeat it a few times during the morning. (Elisabeth, assistant, 13.12.2002)

Sofie clearly benefits much from being part of the group of non-disabled children. Children learn how to deal with each other. Not only for Sofie but also for children without disabilities, there are clear benefits: children learn to be patient and to adapt to the pace of someone who is slower. One of the pupils in my classroom is incredibly hyperactive. With Sofie he knows that the only way to cooperate is by being patient. He learns a lot from it. (Thomas, teacher, 11.02.2003)

There are children who really flourish when interacting with Sofie, children who are otherwise much more quiet. Mira and Zora, for example, don't have great language skills, but when you see how they interact with Sofie, it becomes clear that they don't need a language at all. (Thomas, teacher, 27.06.2003)

Teacher Thomas considers Sofie's situation as an isolated case. He respects the choice of her parents, but doesn't question the policy of 'letting children repeat their year' or 'refer children to special education'. For each individual case, it must be decided whether inclusion is possible. The people involved in this decision are the child, the parents and support workers.

Sofie's parents want their daughter to attend a regular school, so special education is not an issue anymore. That is why we have to do it. Our work is to be committed one hundred percent in supporting her. (Thomas, teacher, 27.06.03)

One of the reasons why I would send a pupil to special education is because I believe that despite all the efforts we have made, we really cannot go any further with this. I know that in special education there is a type of education where this pupil would have been helped. Only in this case, I refer the children to special education. (Thomas, teacher, 27.06.03)

Daniel

Because Sofie and Daniel work together in the buddy system, they have become friends. Daniel has been in her class since third grade. They enjoy

themselves. They spend time together in the classroom, during recreation time or at noon.

This afternoon the teacher called Sofie to order: she was constantly playing, caressing and laughing together with Daniel. The teacher asked her/them to pay more attention: now we are still working! It was noticeably more quiet. (Elisabeth, assistant, 05.09. 2002)

Daniel patiently resolves our food tube problem. He fiddles and fiddles. I boil water and let the food tube soak. Daniel uses his teeth and muscles to get some movement in the solidified milk. (Elisabeth, assistant, 14.03. 2003)

During lunch break, Sofie tells us that she wants to hug Daniel because he can't come along on our field trip. (Ilse, assistant, 25.04. 2003)

Sofie shares her material with Daniel, which makes the teacher angry.

The teacher has an appointment on Friday with the day care centre of Daniel. He will pass on the agreements made because he does not think it is right that Sofie lends material to Daniel the whole time. In this way he will never learn to take his responsibility. (Ilse, assistant, 10.10. 2002)

Daniel doesn't put a lot of effort in his school work and most of the time he is not in order. The collaboration between his father and the day care centre does not always proceed smoothly. Thomas is not happy about the way things go with Daniel and repeatedly expresses it in the classroom. Sofie is worried and wants to help Daniel.

We started with a number of math exercises. After a few minutes, it was clear that something was wrong. Sofie was very restless. The teacher gave us permission to go to her private room to finger out what was wrong. After I gave her a big hug, Sofie already felt a little better. When I took her book, she indicated that she wanted to tell me what was wrong. It was very difficult to work with questions because she was too nervous.

Does it have something to do with school? Yes.

With the test results? Yes.

Yours? No.

Other children? Yes.

Are you a bit nervous? Yes.

Are you worried about the report of other children? Yes.

We went through the pupils and arrived at Daniel.

We then briefly talked about it and I explained why the teacher was sometimes angry at Daniel. After a while we returned to our class. The teacher also explained it to Sofie. She felt a little better, but I suspect she is still worried. (Katrien, assistant, 27.01. 2003)

I couldn't discover more. Only ... that Sofie is worried about Daniel's bad tests. It has nothing to do with the teacher directly. She wants to tell me using her communication book, but it doesn't work. Maybe you have better luck. (Rita, mother, 27.01. 2003)

Together with Susan, we found out what had been on Sofie's mind the last days. It was an incredibly moving conversation. It's amazing how many facts play in her head. I was astonished by it.

Are you worried about Daniel's report? Yes.

Do you think you can tell it with your communication book? No.

Should we ask questions? Yes.

Is Daniel a great friend of yours? Yes.

Do you want to help Daniel to obtain better test results? Yes.

Do you have some ideas on how to handle it? Yes.

Would you help him at school? No.

Would you help him at home? Yes.

Would you help him with reading? No.

Do you want to help him with math? No answer.

Should Daniel do his homework and come to learn his lessons at your house? Yes.

Do you want to show Daniel when he should work and when he can play? Yes.

Do you want to make sure that his school work has been done? Yes.

When? At the weekend? Yes... On Mondays and Thursdays too? Yes.

Why do you want Daniel to have better results? So the teacher would be less angry? Yes.

Do you want Daniel to be in your class next year as well? ? Yes.

Can Daniel do better? Yes.

Do you know what Daniel's life is like? No.

Do you want to know more? Yes.

Has Daniel told you anything yet? No.

This looks like a job for Sofie and Elisabeth: asking Daniel where he lives, how he lives and where he comes from.

Do you want to talk to your parents about solutions? Yes.

Maybe we have to talk to Sofie about mothers and fathers who are no longer together. She really thinks about this. Sofie wants to know more about it: what does it mean: 'being separated'?. She wants to help Daniel. (Katrien, assistant, 28.01. 2003)

In their spare time, the two children spend more time together. This is a way for Sofie and Daniel to have fun together. Invitations come from both sides.

Daniel asks me if I can come with Sofie to the Totem tomorrow (day care centre). There is a party. I have asked him when the party starts and ends, finishes and where it is held. If it is not far, perhaps we should pop in? (Ilse, assistant, 30.01. 2003)

We would like to ask Daniel to come along to the game factory with Sofie. Maybe you can already check it out? Toon could phone Daniel's dad tomorrow evening so they can meet up. (Rita, mother, 30.01. 2003)

Sofie has questions about the Totem party last Friday.

Do you want to talk with Daniel? Yes.

With whom do you do that? Susan? No. Katrien? No. Ilse? No. Elisabeth? Yes.

About what? Party? Yes. Totem? Yes. Saturday? No. Dad? No. Home? A little.

How was the party? How are things at the Totem? What do you do there?

How is home? (Katrien, assistant, 04.02. 2003)

It isn't always easy for Daniel. This is reflected in his behaviour. He tries to make up with Sofie and her support workers. This also become more clear for the teacher.

Sofie was very pretty. It was fun to walk in the procession, although it was very difficult with Daniel. A comment or question towards him makes him become angry and start swearing. I felt upset. I was very happy that he came to apologize this afternoon. "Miss Ilse, sorry for those things, eh." Me: "It's OK now, nice of you to come back at those things." Daniel: "Yeah, you were so sweet and I was angry." I told this to the teacher, I thought this was very brave. I go home with a good feeling. (Ilse, assistant, 28.02. 2003)

The situation with Daniel escalates in class because there are more and more conflicts with him. The buddy system with Sofie is explicitly used to punish or reward Daniel. The concerns of Sofie and of the support workers make the teacher more compelled to find a solution for Daniel.

Sofie's day could not have been better: Daniel as buddy! But when checking Daniel's homework, the teacher found out he didn't write his punishment. Daniel had to go into the corridor to finish his punishment. Furkan joined her there until Daniel was ready. I explained to Sofie why this happened. She understood, but was disappointed. I can really understand her feelings. (Katrien, assistant, 18.02. 2003)

Daniel has not done his school work, his school diary has not been not signed and he has forgotten the money. As a result, he is not allowed to sit next to Sofie for the first two hours. It becomes increasingly difficult for Daniel. He quarrelled on the tram with Durim yesterday. We cannot reconstruct how it started, but it is clear that there are many facts that can't be explained. Thomas and Nelly (his brother's teacher) are going to talk about it on the staff meeting tomorrow. The children haven't gone to the Totem the last two days. I fear there are not many alternatives. Patience is running out. Not a hour goes by without a comment. (Elisabeth, assistant, 19.02. 2003)

This morning Sofie was upset because Daniel was not there. Thomas sent him to the principal for a conversation. Teacher Thomas let me know that they had tried everything, but they would soon have no other choice. His behaviour is really unacceptable. Together with the principal, teacher Thomas is working on a solution. That's what the teacher said to Sofie. The moment Daniel entered the room, Sofie followed him immediately. (Julie, student, 20.02. 2003)

Daniel is today's buddy until recreation time. He is very enthusiastic. The teacher comes to Sofie and tells her that together with Daniel they found a solution to his problems, but it's still a secret between Daniel and the teacher. He's going to tell us more about it on Friday. (Katrien, assistant, 24.02. 2003)

Daniel joined us to read books. We read about the crocodile and the gorilla. He asked us to meet again. I explained to him about Saturday. Everything would work out for him at school. The Totem (day-care centre) and his dad were informed that Daniel must take better care of his school work. This will also be important to him later in his life. He has a hard time at home, which is confirmed by the Totem. (Elisabeth, assistant, 27.02. 2003)

Confrontation with being different

Sofie is increasingly confronted with differences. She eats differently. She can't always participate in the same way. This gives her grief and makes her feel disappointed.

During the afternoon Sofie wants to tell us something.

About school? Yes.

About now? Yes.

About food? Yes.

Can you tell it with your communication card / book? No.

Your food? Yes.

Milk? Yes.

With the communication card: I do not know.

Do you want to know why you drink milk and I eat sandwiches? Yes (very intense).

I explain to her why she finds certain activities difficult, emphasising what she CAN do. Maybe we need to focus more on this subject and talk about it with the teacher? (Ilse, assistant, 26.09. 2002)

In class we soon begin to practise the peace song. The teacher starts to play his recorder. First Sofie likes it, but suddenly she begins to cry sincerely. I really don't know what's going on and we decide to go to her private room. There, Sofie becomes quiet. We check her diaper and her fever, but everything is fine. Sofie doesn't feel any pain. She can't tell us anything with her communication book. Beste informs us that they are going to practise with the third grade. She rubs Sofie's arm for a moment. Sofie also wants to join her downstairs. As we enter the dining hall, all/the children are very concerned about Sofie. Aysel and Stefanie take place beside her and do not move from her side. There are many questions about why Sofie cried. The teacher thinks the song might move Sofie very much. She's already a little older, so maybe she realises the impact of war. For a moment she feels a bit better, but then she breaks back into tears. Together with Aysel we go outside. Aysel explains that if she cries, we also feel very sad. Can you tell us something, Sofie? It is the song? It is the noise? Are the instruments too loud? Are you in pain? Is there something wrong with the class? Is it the teacher? We go back to her private room. Sofie can't tell it with her communication book. We hug briefly and then continue with questions. Sofie regrets that she can't sing. She would also like to sing for peace. She agrees to work with the Big Mack to sing the chorus. When we enter the classroom, we tell the children about it. Teacher Thomas will sing even more loudly for Sofie. Stefanie gives her own mud-toy gift: You don't need to be sad, Sofie. For Derya it doesn't matter that Sofie can't sing along, maybe she can think very hard of peace: "That's also important, Sofie!" (Elisabeth, assistant, 21.03. 2003)

The above example shows that feelings of frustration are caused by her inability to communicate.

When Sofie came home, she could either rest a while, do her homework or talk about Marjolein who had been to Istanbul. She chose the latter. But we didn't get very far. She was excited, very restless, constantly using her hands ... Working with her communication book started to frustrate her and little by little us. Susan is right when she says that Sofie needs the voice

computer as soon as possible as a communication tool. This is a priority. (Rita, mother, 04.11.2002)

After reading the second page, Sofie starts to wave her arms and legs quite intensively. I try to talk to her so she could keep still because otherwise we can't communicate. I think this is the only thing we can do in such a moment, talk to her. We go out of the classroom for a while. Are you in pain? No. Are you sick? No. Does it have something to do with class? Yes. With reading? Yes. Sofie couldn't read the second page. Her book support was not straight enough. Where should we put the Big Mack? She could not say. (Ilse, assistant, 28.11.2002)

Sofie is getting very sensitive about her nursing. She does not like it that the care needs to be done by assistants. She wants to keep it as private as possible because she feels ashamed about it.

This morning she wanted to tell us something. She came back on the diarrhoea-incident of last week. She found this very annoying and felt very ashamed! Because she is getting older, such situations become more difficult for her. (Rita, mother, 08.09.2002)

During the lunch break, Sofie indicates the word 'diaper' in her communication book. She prefers diapers and wipes be removed from her table. She prefers that we hide them in the closet. (Ilse, assistant, 03.12.2002)

Religion: We must complete the following questions. Did your friends ever laugh at you because you lack something? Yes. Was it a video game? No. A piece of clothing/your clothing? Yes. Something for school? No. Something else? No. The next course is maths. Sofie indicates that she wants to tell us something. The teacher agrees that she should do it now. Is it about the sheet we have just completed? Yes. I try to indicate the importance of using her communication card / book. We can't figure it out. Sofie starts to weep. The teacher is shocked because of her reaction. We go out of the classroom. Sofie calms down a bit. I have to ask questions. This is what she answers:

- Children laugh.
- Something she doesn't have something, while the others do.
- Not an object or a toy, but clothes.
- Has nothing to do with her body, disability or her being different

I can't get any further. We try again with the communication: this points at 'assistants'. Meanwhile, we are 25 minutes out of the classroom. We agree that we take a break and will come back to the subject later on. I suspect that it has something to do with the diaper/nursing. I feel really bad because I couldn't figure out what Sofie wanted to say. (Ilse, assistant, 09.01.2003)

I think the mystery is solved.

Children laughed at something she does or has.

Kids = friends.

Does it have anything to do with your disability? Yes.

She indicated 'diaper' in her communication book.

Can you tell us who laughed? Yes.

Do you want to say it? No. (Rita, mother, 09.01.2003)

Sofie at home

Sofie and her parents have gone through a lot together. Toon and Rita have already shared many experiences with Sofie and know her history. They have fought (and fight) a lot for their daughter and have tried their utmost to give her a good quality of life. As a result, they are not easily thrown off balance.

We knew from the beginning that Sofie could have a very serious disability. Often this differs from other parents: they almost always have to make new concessions, always re-accept their child won't be able to do this or that. We had nothing, we thought we had lost Sofie. That 'battle' has determined our whole attitude. We have a reputation to be quite persistent; this is how we have always been able to acquire small things. (Rita, mother, 18.01. 2003)

What happens to Sofie in the classroom is still very important at home. A lot of conversations focus on her experiences at school. Clearly, her parents are very interested and very involved in what she is doing at school. At the weekend, much time is spent on making homework together.

Sofie got a heritage from Toon: a pair of compasses. She was really excited. And it works! (Rita, mother, 02.09. 2002)

Toon starts with Sofie's food, while Rita is busy cooking in the kitchen. Toon first reads Sofie's school diary. "What have you done today?" He reads out aloud what is written. Sofie listens and gives some response. (Elisabeth, assistant, 16.01. 2003)

"Do you go to school tomorrow, Sofie?" Sofie shakes her head and laughs. "Should I call teacher Thomas you can't come tomorrow?" I'm acting as if I'm calling. "Hello, teacher Thomas. Sofie can't come tomorrow. She is VERY ill. She has a high fever." Sofie is very amused. Toon also participates in the game: "Teacher Thomas can't come here. Otherwise, he will be sick too." (Elisabeth, assistant, 04.02. 2003)

Working with a direct budget gives the family a lot more opportunities to tune the support to what they need and to what they find important for Sofie. They need to rely less on standard packages of care.

Toon left at 5.45h. Sofie kept sleeping. She was clearly at ease. The last years, it has become less of a problem if her dad is gone for a few days. The assistants sleep in and dad is probably going to bring a present for her when he comes back. What do you want more? In former days, Sofie used to be quite scared that we would bring her to a nursing centre for a few days. (Rita, mother, 28.11. 2002)

At school

All the teachers know Sofie. This is hardly surprising because there's only one girl in a wheelchair. When these teachers are communicating with Sofie, we can see a clear difference between teachers who taught Sofie and those who didn't. The first group of teachers have built up a stronger connection with Sofie and they keep showing interest.

Teacher Sanne replaces Thomas. She addresses Sofie: "Hello Sofie. I come to see how you are doing in fourth grade". (Elisabeth, assistant, 16.01.03)

Teacher Wim would really like to know the reading progress that Sofie has made. I promised him that you would explain it to him. (Rita, mother, 12.03.03)

Art classes are organised across the different class groups. The children do a variety of activities, such as pottery, cooking, singing, with a different teacher from third or fourth grade. This way, different teachers keep on meeting Sofie. It remains important to see in which group Sofie is: in order to let her participate in the activity she needs some strong buddies.

Pottering with miss Katrien. Katrien makes a lot of contact and tries to give Sofie a place in the group. Indeed some coaching is needed on what she can expect from Sofie. (Ilse, assistant, 13.09. 2002)

This afternoon we went to make braces with teacher Jan. Sofie mainly observes during this activity, but we make a lot of jokes. Maybe we have to take another look at Sofie's group? Of her own class only Tabib is with her. He likes driving the wheelchair, but there is little interaction between them. (Elisabeth, assistant, 20.09. 2002)

Tomorrow Sofie will join the rotation group one more time. After that, teacher Thomas will change the group so it contains some children that have a better connection with Sofie. (Ilse, assistant, 10.10. 2002)

Halfway through the year, the teacher of the next grade starts asking questions about Sofie. We get fewer questions such as: "Is Sofie coming?" but more: "How does it work exactly to have Sofie in the classroom?" Sofie has found her place within the school and moves to the next year together with the other children.

Yesterday miss Nelly grade spoke to teacher Thomas. She wanted to know if somebody was present for Sofie all the time. (Ilse, assistant, 12.03. 2003)

The other teachers and the staff of the school guidance centre regularly ask questions about Sofie's presence in the school. Clearly, her presence has an impact on the school as a whole.

While I was making copies, I had a talk with miss Nadine as well. I told her about the photo and the story. She also thinks that Sofie is opening up. She used to hardly react when miss Nadine asked her a question. Now Nadine sees that Sofie is listening, following and makes herself be heard. "Then it must mean a lot to her, to be here!" For sure! It also is important to Sofie that strange people receive these signals from her. Miss Nadine says: "I used to think that maybe it was all too tiring for Sofie." Sofie was indeed very alert and concentrated at the start of this school year. I find it striking myself. (Elisabeth, assistant, 18.09.2002)

5.6. Fifth grade

The beginning

The schoolbag is ready. Sofie is in a good mood. And so are we! However,... she's also a bit nervous. A good start to everyone! (Rita, mother, 01.09.2003)

Sofie is very awake today. Everyone gets his/her laughs, she's happy to be back. (Elisabeth, assistant, 01.09.2003)

To take space

Sofie takes up much space in the classroom. When she arrives in class, the other pupils need to literally make room. The classroom is being reorganized. Sofie brings along a large table where she can fit under with her wheelchair and where both the partner, the assistant and the teacher (sometimes) are able to sit at. There is a separate table for the assistant, where adjustments can be made. This is also giving more physical distance between Sofie and her assistant. Sofie also brings along a separate table with her computer and her stabilizer. In the class of miss Nelly, this means giving up the sitting corner with pillows. It is also necessary to have an accessible way to and from Sofie's place.

We have installed Sofie at the big table, because it seemed the most comfortable position in the end. All of Sofie's material is in place. I have put it all on the grey desk that still stands in the corridor. I will take Sofie's material into the classroom. Miss Marjolein has moved the stabilizer from the gymnasium to the class. (Elisabeth, assistant, 01.09.2003)

Miss Nelly

A close relationship is growing between Sofie and Nelly. The teacher is uncertain about who Sofie is and tries to see how she reacts. Nelly is very open and curious. She goes for it.

I was happy to see Sofie again, especially when I saw that she was glad to be back. She responded to my question very enthusiastically. What an adorable child! (Nelly, teacher, 25.09.2003)

The teacher couldn't sleep last night: what did Sofie want to ask her? (Elisabeth, assistant, 24.03.2004)

Miss Nelly sighs and says: "Would you believe I'm going to miss her next year, our Sofie? (Lynn, student, 29.03.2004)

Miss Nelly sees that Sofie learns and can learn. Throughout the school year, there has been a positive cognitive evolution. Furthermore, she increasingly determines what Sofie has to learn and what she experiences as essential.

The children have to practise a French dialogue. Sofie is Louis. She presses on her Programme. The teacher was surprised that Sofie is involved so much. (Ilse, assistant, 03.09.2003)

During the test, Nelly came to see how it went with Sofie. Sofie gave her a really friendly smile. Miss Nelly was really impressed by everything that Sofie has learned. She sees real progress. (Elisabeth, assistant, 14.01.04)

We practise on percentages. I find this hard – The teacher thinks it is important that Sofie knows that discount means that you pay less. (Tessa, assistant, 17.01.2004)

Gradually, there is more interaction between the teacher and Sofie. The teacher herself starts working with Sofie and makes time to learn how to communicate with her. She tries to better understand Sofie's perspective. She takes her responsibility in relation to this student and her parents.

The teacher asked if her board text (cardboard flaps with magnets hung on a board) was big enough. Sofie said 'yes'. (Tessa, assistant, 05.09.2003)

The teacher explains that yesterday Sofie very clearly shook "no" at her question. The teacher really does her very best to interact with Sofie. Sofie tries to respond clearly to the presence of her teacher. (Elisabeth, assistant, 19.11.2003)

School evaluation: I look at the school results with Sofie. The teacher asks the pupils if they have any questions. Sofie has got a question. She asks her teacher if she could go through her results with her. The teacher is glad to make time for this. Then the teacher has got a question for Sofie.

She wants to know if Sofie's song can be used as a melody for the great teacher song that she wants to make with the class. That is not a problem at all! (Lynn, student, 29.03.2004)

Hi Rita. So I talked to Sofie and made clear that she must learn to accept that she has some restrictions in abilities. We have also made agreements about tasks and homework. If you have comments, please let me know. You can always call me. (Nelly, teacher, 01.06.2004).

Miss Nelly encourages Sofie in a positive way. She is proud of Sofie's achievements and regularly shows this.

Sofie was in a zealous mood. She began her test right away. A good day, girl! (Nelly, teacher, 06.11.2003)

The teacher corrects Sofie's test while the others are still working. Sofie gets compliments from the teacher: "Very good test! You have worked hard. Almost everything is correct. Congratulations! I would like to start every day like this." (Lynn, student, 22.03.2004)

Within the daily classroom practice, the emphasis for Sofie is on participation and involvement. Sofie is pleased to be part of the group. Significant adaptations are made. Miss Nelly shows interest in what Sofie is doing and her way of working. Towards the end of the school year, she actively creates more relaxing moments for Sofie.

Good work today! Sofie was happy to be involved again. (Nelly, teacher, 25.11.2003)

Miss Nelly was impressed by the way we are always able to search for a link between what Sofie is doing and what the other pupils are doing. (Elisabeth, assistant, 19.03.2004)

The teacher comes to talk with Sofie. She has not slept all night because she finds it difficult to tell Sofie truth without hurting her. Miss Nelly does this in a very nice way: she says that she likes Sofie, and that it is weird if she does not come to class. However, she adds that it is important that Sofie listens to her own body. If she is tired, then she has every right to rest, even in the classroom. The teacher forbids Sofie to do homework after school. After school Sofie needs a good rest, she must relax and do fun things. She has worked hard throughout the school year and must enjoy the last month. Sofie agrees and laughs. (Julie, student, 01.06.2004)

Miss Nelly plays an important role for the other children. She puts Sofie in the middle of the group and encourages the other pupils to communicate with Sofie.

The teacher is rightly proud of Kader. She helps Sofie by keeping the colours in front of her while colouring. Sofie grabs them. Great to see this! (Tessa, assistant, 06.10.2003)

The teacher looks through the window as we drive the Adremo. Afterwards, she lets the classmates come and see this: an audience! Sofie received applause from the other pupils the class. She did great. (Tessa, assistant, 04.12.2003)

Miss Nelly allows Sofie to answer more regularly during classical moments. (Elisabeth, assistant, 05.05.2004)

In the fifth grade, the work pace is higher. They expect the pupils to be more independent. Discipline and structure are key words within the classroom practice of miss Nelly. There will be tighter agreements to monitor. Cognitive learning is taken seriously and is considered as a preparation for secondary school.

I talked to the teacher and agreed that we would not talk in the classroom (only with Sofie of course!). If we wanted to discuss something with assistants or therapists, we would go outside. (Ilse, assistant, 02.09.2003)

New agreement: When we go up the stairs with the platform lift, the partner does not join us anymore, because then he/she is too late in the classroom. From now on, only the assistant is going up with Sofie. (Tessa, assistant, 16.09.2003)

The teacher stays the teacher. Assistants complement her role and ensure that Sofie can participate. The relations will shift as time progresses. There are questions and proposals from both sides: both the teacher and the assistants learn how to cooperate better with each other.

On Friday the children received their results. Miss Nelly wondered how she could give Sofie marks. I said that Sofie also receives a school evaluation. (Tessa, assistant, 06.10.03) I'm using exercises to make a survey on what Sofie did. The teacher makes the evaluation. (Ilse, assistant, 08.10.03)

Miss Nelly says that we can always ask her for additional explanation about certain exercises. That is not a problem for her. What they learn, becomes more and more complicated. It is not always obvious anymore. (Elisabeth, assistant, 07.11.2003)

Sofie did a geography test in her private room during French: She made mistakes, but noticed them when she was reviewing the test. Let's see how the teacher will evaluate it! (Tessa, assistant, 02.12.2003)

Miss Nelly is doing classical exercise on fractions. Sofie looks at me. I give her a sign that she has to look to the blackboard. The teacher sees my gestures and reacts accordingly: "Sofie, can you pay attention?" (Tessa, assistant, 09.03.2004)

Miss Nelly explains Sofie's condition? to the other members of the school team. Moreover, she takes care of Sofie's interests at staff meetings and informs support workers on what is decided within the school.

During yesterday's staff meeting, miss Nelly obtained that Sofie can park in front of the school to get in and out of the car. This will be a lot easier for her. The principal agreed. (Elisabeth, assistant, 07.11.2003)

Communication

Sofie feels a need for more communication to make clear what she wants. She communicates with more and different people in different contexts. She mainly answers yes/no questions and she uses communication cards with bliss symbols on her table.

Nelly, during lunch break I briefly talked to Sofie and she asked (very clearly and firmly and with many words and clear yes / no):

'Classmates' - whole class? No. A part? Yes.

Aysel? Yes. Others? Yes. Kader? Yes. Others? Yes. On the map? No. In class? Yes. Ulvi? Yes. Others? No.

Another word? Yes. 'Swimming'.

Conclusion: Sofie wants to know if Kader, Aysel and Ulvi may go swimming with her during the holiday. (Tessa, assistant, 15.12.2003)

For the first time Sofie used spelling to communicate.

Sofie has to answer some questions about herself. With the communication book and Beste (on the letter card): t, i. Tiger? Yes. Favourite pet? Yes. (Ilse, assistant, 06.11.2003)

However, she also experiences more difficulties communicating with others. It occurs more frequently that Sofie can't express herself clearly and/or those around can't understand her. To tell something more yourself or to cut a new subject requires a more complex level of communication.

During lunch break: Sofie wants to tell us something. "I do not like this." Another word? Yes. 'I'. Another one? Yes. From here on it goes wrong. It was already a difficult process to get to this point. It is not clear if she answers yes or no because she gives both answers, one after the other. She continues doing this but it is really unclear what she wants to say. We can't figure it out. I ask her to try again. (Tessa, assistant, 09.12.2003)

Towards the end, it becomes more difficult: Sofie is getting tired and gets tears in her eyes. She wants to wait until the afternoon to say what's wrong. She says she has a headache, which is painful when the teacher occasionally raises her voice. . Sofie seems a bit upset: she has a restless body. I can't figure out why. Sofie says that it's hard to explain. Even with the book we didn't succeed to clear things out. Rita, Sofie says that she wants to talk about it tonight. (Julie, student, 04.05.2004)

Sofie answers with the following two words: 'jacket' and 'daddy'. I ask her if her dad has got a new coat. Sofie does not really answer. I try all possible variants on jacket ... We can't figure it out. The life jacket and Sofie's coat are still in her private room, as is her swim gear. I ask her if it has to do with the life jacket. Sofie gives an unclear yes. (Lynn, student, 14.06.2004)

In class and during leisure time we work with communication cards on a particular subject. There is a communication card around 'shopping', 'swimming' and 'scouting'. These communication cards are used extensively. Sofie makes them together with Susan, the speech therapist.

We are searching for symbols for a swim card, because Sofie asks for it. Map symbols: in - out / cold - pool / Fun - life jacket / clothes on - toilet / cap - not / swim - someone, a person / swimsuit. (Julie, student, 23.03.2004)

A new communication system has been installed on Sofie's computer. It takes a lot of time to familiarise ourselves with it. It is difficult to practise during the lessons. Sofie is not really fond of this new system on her desktop computer. It is not the same as a voice computer. She refuses to work on the computer during speech therapy because the motor control of the computer remains a major problem.

Sofie clearly indicates that she no longer wants to work with the computer, not even during gymnastics. Why not? Too difficult (operating). She doesn't even want the Tellus (voice computer) anymore. She refuses to work with it because it is too difficult to operate it and to do exercises on it... (Tessa, assistant, 03.02.2004)

Voice computer - There has been little progress, which is caused by several factors including the motor skills of Sofie and the change in assistance. Many people find that this should really be a priority for next year. It is clear that Sofie has an increased need for communication, and also in games there is a change to much more verbal interaction. In this regard, the voice computer is of considerable importance. A voice computer is not Sofie's class computer. Perhaps Sofie doesn't believe that she will finally get one because they have already been talking about it for a very long time. As long as she does not actually see the voice computer, we will give her no prospect that she will be able to intervene more quickly. Many questions still remain as to how exactly the voice computer should be operated. Susan (speech therapist) is concerned that frustrations could slow down the use of the voice computer. (evaluation 5th grade)

Kick off a new assistant.

Tessa starts as a new assistant. She is not familiar with Sofie through training and starts in the fifth grade where the pace is much higher than before. Two students replace Tessa as she decides to change jobs halfway through the school year. It is not easy to deal with this change in support.

The new assistants can contact the parents and their more experienced colleagues to walk along, ask questions, call and email...

First day: it was a pleasant surprise to see how other children are involved in Sofie's activities. Sofie could help with crafts, hurray! I received many explanations and tips received from Ilse, and decided to go for it. . The cannula and food tube are new to me, but I will learn it through practice, and if necessary I will ask for help. Sofie's smile is worth gold; hopefully I'll get to see it often. You can immediately see that the relationship between Sofie and Ilse is close (Tessa, assistant, 02.09.2003)

Much is expected from assistants, a lot of responsibility and two people who have supported Sofie for a long time. Many things are taken for granted and not fully explained. This was indicated by Tessa, Lynn and Julie. (...) Additional consultations among assistants and Rita are necessary. (evaluation 5th grade)

The first day, there was uncertainty for both the giver and the receiver of support.

It was the first day for us. I have the impression that Sofie was looking for Ilse and Elisabeth: she constantly looked around the classroom and then back at me. But come on: we will try to have a nice day. (Tessa, assistant, 05.09.2003)

Sofie helps me by explaining how I should guide and support her. She is an important source of information to know if you are adopting the right approach. Meanwhile, working together with several people brings a sense of insecurity: Sofie likes to know that the supporters know what they (should) do.

The afternoon was fun: Beste and Daniel came to see us. Sofie laughed a lot. I think the two of us make a good team! Sofie helps me a lot by clearly saying 'yes' or 'no'. (Tessa, assistant, 05.09.2003)

During dinner, Sofie makes it clear to me that she wants to say something. Do you want to tell me something? Yes. About today? Yes. About something that happened in the classroom? Yes. French? No. Arithmetic? Yes. Feelings? No. Something we have done? Yes. Explanation about the teacher? No. About exercise? Yes. Too much? No. Too little? No. Too difficult? No. Too easy? Yes. I've apologized a thousand times. (Tessa, assistant, 02.10.2003)

Sofie wants to tell me something.

- With questions and she can't give a keyword with her book
- Past - present - future
- Home - School - surgery - scouts
- Camp - swimming Sunday

Sofie was worried about whether I would know what to do before she goes in the swimming pool. I had to promise that I would ask her mother, father and Elizabeth for clear information and instructions. (Lynn, student, 22.03.04)

There are lots of questions. What is Sofie able to do? What can you ask her? How do you offer educational support to Sofie? What do you ask the other kids? What can you do within the classroom and what not?

What do you let the buddy do? We make a list. (Tessa, assistant, 05.09.2003)

During French classes, the pupils take a test on the second unit in the course book. : Sofie has not seen this yet. What is usually done when she misses classes? How does she catch up for this (Tessa, assistant, 15.09.2003)

Ilse: Would you please bring the tests of the fourth grade? I know that we put them aside but can't find them anymore. I think it makes sense for me to see this to gain insight into Sofie's abilities. Thanks! (Tessa, assistant, 16.09.2003)

If something is placed on Sofie's shelf (handkerchiefs, her communication book) while you move, then she wipes her handkerchief, book... off the table. At first I thought this happened in an uncontrolled manner, but since last week I am not so sure. What do you think, Rita? What do you think ,Elisabeth and Ilse? (Tessa, assistant, 01.12.2003)

Adaptations

In the fifth grade, we need to make more and bigger adaptations. These have to be made more systematically. We see several ways to make the contents of the curriculum accessible to Sofie.

There are essences determined. What are the main goals? Sofie should not learn everything the same way and in the same amount as her classmates. Everything requires more time and effort. What is the most meaningful and useful to her? This determines the goals of the content.

I have now finished compiling a word list for the sixth unit in the French course book. Could you please check if the words I've selected are the most common ones? (Tessa, assistant, 06.10.2003)

We learn about relief. What does Sofie learn?

** Relief = high / low landscape*

** Difference between a mountain and a hill*

** To be able to indicate the level of a given region (by extending previous legend)*

** Knowing that Belgium is divided into low, middle and high Belgium.*

(Ilse, assistant, 04.02.2004)

Sofie always needs physical support to learn. She does the work, but another person is often involved in the execution of the task. You always

need to look for the right balance and you need to recognize Sofie's contribution.

Arithmetic: perimeter and area. Sofie follows along in the group. Exercise: I draw the figures on a white sheet, large and in bright colours. Sofie holds the slat, I measure. Then we count all sides = perimeter. I also explain the difference between perimeter and area again. Then I calculate some figures. Sofie says if it is the perimeter or the area. (Ilse, assistant, 01.10.2003)

Sofie works more with concrete materials. This makes learning visible and tangible?, it helps her to understand and memorize it.

During arithmetic we learned about spatial orientation. We had to build an apartment and then draw the side views. It was difficult to adapt this for Sofie and Sofie found it difficult to understand. I tried with blocks of different colours to make it clear to Sofie. (Lynn, student, 07.10.2003)

French: we have worked on the following concepts: 'derrière', 'sous', 'sur', 'devant' and 'dans'. With the box of handkerchiefs I applied the concepts. Pen in the box = sous or dans? Sofie understood it. (Ilse, assistant, 03.03.2004)

When communicating with Sofie, we formulate a lot of the questions in multiple choice format. Giving options enables us to work with a gaze framework where Sofie can give an answer by looking or by asking yes / no questions.

Language: Schedule for the spelling of the verbs. I posed the following questions: Jan rides home. What is the verb? What are they doing? Two possibilities were given: cycle - home. Does the sound changes in the past? Yes or no. (Ilse, assistant, 05.02.2004)

We start from the teaching materials that are developed for all pupils and then adapt them to Sofie's needs and ability. There are many modifications made to make it more visible and to put less on a sheet. The amount of material is seriously reduced, which gives us more time and space to study the materials.

Adaptations for next week: arithmetic: pp. 117-121: geometry: is decreased and in order. (...) pp. 122-124: The lesson is adapted in the book. We may still need to drop some exercises. (Ilse, assistant, 05.11.2003)

Test geography: can you please go through the lesson material with Sofie and ask her what lesson she would like to repeat? She may repeat a maximum of two lessons. (Tessa, assistant, 01.12.2003)

Within the same theme, there are different expectations to Sofie. She works with single and simplified tasks.

We make the differentiation exercises of arithmetic. Sofie works quietly, but is very focused. We practice on addition/subtraction/multiplication and division from point numbers. I try to work with the table of 10. This requires less effort and Sofie deals mainly with the commas. 0.48: 0.12 becomes 0.8: 0.2 (Elisabeth, assistant, 19.11.2003)

These adaptations require a lot more organization. They take up a lot of time outside the classroom, during noon or during therapy. The work is divided among several assistants and Marjolein, the speech therapist. This requires mutual agreements and communication so that Sofie has got the necessary material in time. The teacher gives her a week planning and discusses what is important for Sofie. Materials are rarely adapted ad hoc.

Today I would like to make an agreement on adapting books and reading texts. Then I can start to adapt again. I ask the teacher if I may take the language book with me because I would like to adapt all the texts. The French book is adapted, especially the dialogues. When the teacher passes on her programme, Ilse / Tessa / Elisabeth let me know what the content of the language lessons will be this week. (Marjolein, speech therapist, 03.09.2003)

Could you please put all the adjustments made by you or Marjolein in the green folder? If we do not agree on a common place, adapted materials are not found or you find it among other papers. (Elisabeth, assistant, 26.11.2003)

Arithmetic: a new exercise is presented, namely dividing with more than one number in the divisor. Do we already teach this to Sofie or do we wait a little longer? (Tessa, assistant, 09.12.2003) Maybe we can try it, but only with the tables she already knows? I have discussed this with the teacher. She thinks this is the most useful. (Elisabeth)

Other children also use Sofie's adaptations. Some children who are non-native speakers of Dutch also benefit from a more simplified text.

Agreements made with Miss Ellen on language: We will pass on all the sheets that we adjust for Sofie to the teacher. Durim in her class will also use them. After a few weeks we will see how this goes and if it works for Durim. (Elisabeth, assistant, 11.07.2003)

Sofie

Sofie dares to show us her opinion en tells us what she thinks. She appears to be more resilient.

Sofie said: I do not like this. There are two things I don't like: nursing and physiotherapy on less appropriate times, because this causes her to be late in class and to miss a lot more. Do you want the assistant to do this? No. Rather the nurse? No. Well, it is clear Sofie doesn't like it. (Tessa, assistant, 26.09.2003)

At noon Sofie said: 'classmates' – 'mom'. 'Mom of Aysel'. 'To tell something'. 'Questions'. 'To know'. About whom or what? Can you tell me something more? 'Sofie'. Sofie wants to ask Aysel's mother if she can come to play at their house. Aysel says that her mom works and does not come to school anymore. Sofie wants to write a letter. (Ilse, assistant, 08.10.2003)

Sofie is still very sensitive towards what happens in her environment and she adapts to what (according to her) is expected. It is important that we discuss this topic enough.

Just like the other pupils, Sofie has not a new place: in the middle. She agreed when the teacher asked her if she wanted this. (Tessa, assistant, 05.09.2003)

The teacher sometimes stands next to us to do an exercise with Sofie herself. It is clear that she wants to make a good impression on the teacher. (Elisabeth, assistant, 19.11.2003)

Sofie is looking forward to go swimming with Derya during Easter holidays. Derya was crying and Sofie wanted to comfort her. (Lynn, student, 29.03.2004)

Sofie keeps on getting more opportunities to take her own position. This evolves as she grows older.

The teacher asked Sofie whether she wanted to choose the buddies herself (on the condition that the child is not always the same). Sofie didn't not answer. We agreed that tomorrow during the noon break I would figure out if Sofie had any more questions. (Ilse, assistant, 04.02.2004)

Your hairstyle is an issue in the fifth grade. You see that the girls are paying more attention to this, including Sofie. She would like to have long hair. We pay a lot of attention to her hair and how she likes it.

Sofie does not want pigtails, she wanted to keep her hair as it was. (Tessa, assistant, 24.11.2003)

Music is a lot of fun for Sofie. Working with Gertrude (her music therapist) evolves from playing together to making music together. By playing her self-composed songs she can make a bridge to the class.

We have continued Sofie's song. Sofie is very excited about this. She listens carefully to Gertrude and is doing her very best. Besides playing with her feet, Gertrude practises a lot on playing with her hands. She notices progression. Assignment: Sofie has made a song. The notes are on the standing-unit in her private room. We should try to find a theme for the song by next Thursday. Maybe already some words? Sofie is enjoying it. (Elisabeth, assistant, 11.03.2004)

There is a growing tension between what Sofie is capable of and what she wants to do. Sofie wants a lot. She is able to do more because her health is more stable and she can deal better with stressful situations. Nevertheless, rest moments and slowing the pace are necessary to keep it feasible.

It is perhaps a good idea to take into account that we have only a couple of weeks ahead of us before the holidays. Sofie has made tremendous efforts this year. Personally, I would therefore limit the amount of homework. (Rita, mother, 25.05.2004)

Miss Nelly feels that Sofie is really changing. She is growing up and wants more and more. She is worried about what will happen when Sofie feels it will not work. How will Sofie handle this? How do we deal with this? Her desire is big, but keeping a reasonable and slower pace is also important. (Evaluation 5th grade)

There is tension between what Sofie can do independently and where she needs support. The assistants are an important part of how Sofie can show herself. It is a never-ending search for balance: what support is needed? What can give Sofie a sense of autonomy? How can we create more personal space for Sofie and create distance?

Sofie should not rely too much on her personal assistants. We often sit next to Sofie, but Sofie must also learn to do things herself. Perhaps we can look for ways in which Sofie can do a number of things more 'independently' (e.g., audio books, watching TV). We also think of working with the computer. These things are very important to allow her to grow up. (Evaluation 5th grade)

What does Sofie think of the past school year? She evaluates her school year with the same instrument as the other children.

Who are you?

I am smart.

I have a disability.

I can't use my feet and my arms are not good.

I eat through a food tube.

I also have a cannula.

I have a hole in my abdomen to urinate.

I want to learn how to drive with my electronic wheelchair.

I would like to learn more geography and French.

For Dutch, I just continue to work like this.

What do you like in the classroom?

Arithmetic, geography, French, music, singing and playing the guitar, swimming.

I also like horseback riding.

What do you dislike?

Dutch.

I do not like children who quarrel.

How do you work in the classroom?

I use my gaze frame for exercises.

I work with the buddy (classmates) whom I pick on Thursday and Friday.

I work with the teacher and my assistants.

I follow the same lessons like the other children in the classroom.

Occasionally I work with the computer.

I would like more time to work on the computer.

Sofie wants to work with Amelie on the computer, also with Elisabeth, Lynn, Julie and Susan.

How many children are there in the class?

There are 16 children: 8 boys and 8 girls.

Who are your friends?

In my class everybody is my friend.

Of the boys, Adem, Alp, Daniel and Volkan are my best friends.

Of the girls, I like Elif Beste, Ulvi, Aysel, Derya and Kader.

I've also got friends outside the classroom: Emma, Ann and Corali.

What is the teacher like?

I think my teacher is a nice and beautiful teacher.

Miss Nelly can draw well.

I am angry with my teacher if I can't make a test.

The teacher is bad because I can't do more homework.

She has a loud voice and sometimes she shouts.

The teacher is sometimes angry.

I do not like that.

How do you feel in your class?

I like it.

What does a school day look like?

In the morning my mother brings me to school. I like that.

On the playground, I look at children. That's nice, I can also rest.

Ilse, Elisabeth, Julie and Lynn help me.

Ilse and Elisabeth also help me at home, not only in school.

They understand my family.

There are still other persons for me at school: Susan and Marjolein are speech therapists.

Barbara and An give physiotherapy.

Gertrude is making music with me at school. (Sofie, evaluation 5th grade)

The principal

When Trees became principal at school, Sofie went to the fourth grade with teacher Bart. He had many doubts in the beginning.

It is important that he could tell me what he felt and thought. You are not able to provide a solution immediately, but people feel heard. Each teacher has his/her own personality, which often influences the type of questions he or she asks about classroom practice. It is important to take the teacher's needs and questions into consideration, but sometimes you also have to dare to argue. This equally applies to other children at school. (Trees, principal, 24.02.2004)

Trees monitors the process: how is Sofie doing at school? How do the teaching staff deal with it? Much has changed compared to the first grade.

A process that has evolved over several years is further refined and gets deeper roots. As a result, certain aspects have become clearer to all people involved. Sofie goes to the next grade together with her group, although she has her individual plan. Time plays an important role. Each year you notice we have to take a new jump onto the next teacher. Each year everyone gets enough space to ask his/her questions and talk about concerns. (Trees, principal, 24.02.2004)

The principal takes her responsibility if the situation demands it. For example, she offers a helping hand when a building is not easily accessible. Sofie had to move upstairs from the second grade. A construction file was submitted to help and pay for the platform elevator.

You will see that the school is adapted to increased security and accommodation. Through minor or sometimes larger (like the elevator) modifications, the school is really accessible for disabled people. These changes will still be visible, even after Sofie has left this school. (Trees, principal, 24.02.2004)

One of the most important roles of the principal is transferring the work with Sofie to the wider school team. What can we learn from this approach, this supporting method, this formulation of goals ... to teach other children at school? There are many children who need extra support.

We try to draw lessons from the experiences with Sofie and extend them to other pupils, for example children with severe language problems or children who often change places of residence and school. This is not an easy task. Within our team, we try to pay attention to who our children are, what background they have and what their personal experiences are. This is certainly not only for Sofie. When we are discussing the children's progress??, we always try to start from their individual skills and talents. (Trees, principal, 24.02.2004)

The distance between the principal and Sofie is bigger than with other teachers.

You see Sofie at the gate, just like all the other children. It is not obvious to make contact with her. This will surely affect what role you play in her life. A very close contact with Sofie is needed to interpret her body language. I have never learned that in my own education. (Trees, principal, 24.02.2004)

Mainly practical arrangements are made with the principal.

Swimming: The principal told me that they are going to the swimming pool on foot and by bus. It is not a bad idea to drive Sofie by car, so she can stay in the water longer. (Tessa, assistant, 02.10.2003)

Can you bring the Adremo to school next week? I spoke with the principal and agreed that it should be put in the room next to her office. (Ilse, assistant, 12.11.2003)

Scouting

Sofie has joined the scouts. She fits in with the group in her village. This works with the support of Lynn, a student undergoing a training with Sofie in her classroom. She lives in the same town as Sofie. Sofie is very excited about this weekend activity because she will get to know the children in the neighbourhood better.

Sofie wanted to tell me something.

Book? No. Card? No.

Questions? Yes.

About the present? No.

The future? No.

The past? Yes.

School? No.

Home: Yes / No.

Something you've done outside of school? Yes.

Scouts? Yes. Sofie had several questions. Can Lynn take pictures of the children? When can she buy her uniform? If they are wearing a tie, what about her scarves? Then I had to tell her about my experiences in the youth movement. (Ilse, assistant, 25.09.2003)

Nelly, Sofie has asked me if you would write down a few names of friends on her evaluation. It is about children who are coming to your home, from the scouts... I found it difficult to find the names. (Julie, student, 08.06.2004) Sandra, Ingrid and Nathalie (Rita, mother)

Early November Sofie goes on a scouts weekend for the first time. It is a completely new experience not to sleep at home.

Are you glad you've been on scouts weekend? Yes.
Where there moments when you were really happy, i.e. moments that you liked? Yes.
Sneak trip? Yes. Sleeping? Yes. Painting? Yes. Planning theater? Yes. Show fruits and vegetables? No.
Where you sad at any moment? No.
Where you angry at someone / something? No.
Have you been afraid? Sofie laughs and shakes her head.

Sleeping:
Did you sleep well? No.
Were you afraid to sleep there? No.
Were you sorry you had to sleep earlier? No.
Were you tired in the evening? No.
Was your mattress okay or would you rather sleep in a bunk? Okay.
Anything else? No.

Assistance:
Was it fun to go with Lynn? Yes.
Could you do everything with the others? No.
Was that bad? No.
Do you want more rest during the weekends? No.

Food:
Do you prefer to eat alone or with others? Alone? No.
Was there too much noise? No.
Could you understand everything? No.

Show = no fun.
Because you had to go to bed earlier? No.
Because you did not like to dress up as a banana? No.
Too noisy? No.
Too long? No.
Was it a good idea to dress up in fruit and vegetables? No.
Did the other children also think it wasn't a good idea? No.

Do you want to go on another scouts weekend? Yes. (Elisabeth, assistant, 14.11.2003)

Her differences are very explicit in this group. The children and leaders have to get to know her and ask a lot of questions. Sofie is confronted with issues which are obvious at school.

Sofie told Susan that she didn't like the scouts weekend. She did not like the fact that the others looked at her. (Tessa, assistant, 18.11.2003)

Sofie began to cry in the car. After I had asked her some questions, she told that the children of the scouts said something to her that was not fun. She did not want to tell me who it was. She couldn't explain what they said because it was not in her book. She was very sad about it. She didn't want me to do something about it. She just wanted to tell me. (Ilse, assistant, 22.04.2004)

Teamwork

The meeting between the teacher, parents, therapists and assistants is not always easy. As much as possible, Miss Nelly wants to schedule this meeting during the class hours. This appears difficult to achieve because there are few joint moments in the fifth grade.

The weekly programme is very busy. A great deal of attention goes to what happens in the classroom. There is not enough time to practice on the computer, to familiarize ourselves with the communication system and with Adremo-driving.

Susan (speech therapist) believes that there should be fixed times to exercise with the computer programme. This will not be easy because the programme is full! (Tessa, assistant, 02.12.2003)

After the holidays, Susan can come on Monday afternoon. This may be a more suitable moment since the pupils are not there. However, we have planned Adremo driving then... (Tessa, assistant, 03.02.2004)

I have agreed with Susan that we'll organize a meeting as quickly as possible to talk about the communication method and working on the computer. She is worried about this. I've put the dates on email. (Elisabeth, assistant, 10.02.2004)

There is a growing belief that there are a lot of obligations. This requires making choices constantly and this gives moments of friction in the cooperation.

We urgently need to agree about how we're going to adapt the texts for peer tutoring (PT). Today I modified Sofie's arithmetic test and the text of peer tutoring. As you know, there is barely enough time to make adaptations in the classroom. As a result, Sofie loses assistance in the classroom. I have let Sofie follow with Durim and Yener now. (Tessa, assistant, 11.12.2003)

I want to make sure that everything is in order, for example the closure for the cannula, the computer, the Programme ... but I'll do this after the holidays. I really need to be realistic and I don't want to make promises I can't keep. Experience has taught me that the Christmas holidays are a period in which there is little time left: celebrations, family visits, many services are closed... I'll take it on the first week after recess, promised! (Rita, mother, 15.12.2003)

There is less openness to the therapists in the classroom, which leads to tensions within the team.

Susan has problems with the fact that the teacher leaves when Susan is entering. I understand the teacher: she waits until Susan comes to maximise her time in class. Susan expects that the class is empty by the time she comes to work with Sofie, but I think that is difficult. This is an issue for the meeting. Susan looks quite reluctant. (Tessa, assistant, 03.02.2004)

Operation

Much attention is paid to the increased muscle tone of Sofie. This is important because of her physical growth and the handling during nursing. The parents are considering an operation. This information is shared with the other pupils in class.

Sofie had to tell the teacher about the doctor. This is the story. Mum and dad went to the doctor. The doctor told me that something would be placed in my stomach. This would result in being less rigid and limp. First, I will have to undergo tests for one week. Sometimes the doctor will inject water instead of medicine. I will spend some time in hospital. I'm a little scared. (Rita, mother, 11.02.2004)

The class had some questions and comments about Sofie's operation. Can you answer these questions?

1. *When will the operation take place?*
2. *Where will the operation take place? Volkan heard it would take place in Berlin.*
3. *How long should Sofie stay in hospital?*
4. *Can the class visit Sofie if it is allowed by the doctor/nurses? After making an appointment of course, so Sofie is in a good shape.*
5. *At what age can children visit in a hospital? Miss Nelly thought that the minimum age was 12 years because of the risk of infections.*
6. *How long will the operation take?*
7. *Can her dad (doctor) follow the operation?*
8. *When will Sofie return to school? (And she's not gone yet!) How long will she be absent?*
9. *They will miss Sofie.*
10. *Is the surgery dangerous?*
11. *Daniel: Without Sofie I'm not happy.*
12. *Volkan wants Sofie to write back and sends the class letters.*

Sofie wanted to answer certain questions. We go through the questions. She says whether she can or wants to respond or that her mother should answer.

1./2./3. mummy has to answer.

4. *Yes, she wants them to visit her.*
5. *Sofie thinks there is no age limit for children to visit her.*
6. *Mom / Dad can't answer these questions.*
7. *Yes, dad can be there.*
8. *Sofie thinks she will be away for two weeks.*
9. *Sofie laughs.*
10. *Sofie says not. Mum / Dad are well informed.*
11. *Sofie is happy.*
12. *Yes, she will write back. (Tessa, assistant, 16.02.2004)*

Answers to questions:

1. operation might be at the end of the school year
2. in Leuven or Ghent
3. 1 week and then another two weeks

We can discuss in our team how we can follow this up. (Rita, mother, 16.02.2004)

Because Sofie is very occupied by the surgery, she always comes back to this. The various visits to the hospital raise other questions.

Susan: Sofie wants to say something. Daddy. Cap. Question for dad: Does daddy need to wear a special hat, apron, mask during Sofie's surgery? I ask her to tell me some more: it is difficult to explain. Word? Operation. Susan will put the symbol on the communication map. There must be a hospital card. Sofie wants to know what the difference will be between and after the surgery. Susan explains this. Sofie listens very carefully to Susan. Another question: where exactly will the medication box be located in her body? (Tessa, assistant, 17.02.2004)

Sofie wants to know who will operate her of all the people who were present yesterday.

Are you sure it will happen in Ghent? No.

Can it still happen in Leuven? Yes.

Preference? Yes.

Would you prefer in Ghent? Yes.

Was it alright yesterday? No.

Were you scared? Yes.

Was it boring? No.

Was it interesting? No.

Did it hurt? Yes.

Have you been examined on the table? Yes.

Did that hurt? Yes.

Was it the doctor whom you think will perform the surgery? Yes. (...)

Do you have any questions? Yes.

Can you explain? No.

May someone sleep in my hospital room from the first until the last day? Yes, she wants to know.

Do you want to know who will nurse you? Yes. (Tessa, assistant, 16.03.2004)

Sofie would like to know if the teacher would come to visit her after the surgery. (Rita, mother, 03.24.2004) The teacher replies that she will definitely come if she has the doctor's permission. (Ilse)

Sofie wanted to know if she could still ride a horse with the baclofen. She'll probably still have a few more questions. (Rita, mother, 19.04.2004)

Ultimately, the problems can be solved through medication. A dose of baclofen administered through her food tube proves to be sufficient to relax her muscles. The operation no longer appears to be necessary.

What will the future bring?

Ann (School Guidance Centre) asks me what the goals for secondary school are. She wants to discuss with us, in so far you still need it. She thinks highly about Mariagaard in Wetteren and St-Paulus in St. Denijs. (Ilse, assistant, 06.02.2004)

Next year, finding a secondary school is a priority. This topic has been extensively talked about in our team. It would be a good idea to gather these different ideas. This will be an exciting search with all the people involved. The result of this search should really be a team effort. Another priority is developing a more defined and individual programme for Sofie. All the different team members have to look for ways in which Sofie can be involved in this process. (evaluation 5th grade)

5.7. Sixth grade

Sofie

Sofie gives a short introduction of herself in the classroom.

Introduction: give a typical feature of yourself. I start with some questions:

- 1) Something about your appearance? No.*
- 2) About who you are? No.*
- 3) About your disability? Yes. Wheelchair? Yes.*
- 4) What was the best of the holidays? Scouts camp? Yes. (Ilse, assistant, 01.09.2004)*

Sofie is named and represented by other people. The way people close to her look at her and talk to and about her offer important guidelines for the environment. Sofie becomes Sofie in strong connection with her allies.

My maths-superwomen got started as rocket. She was unstoppable. But it also went very smoothly. (Rita, mother, 07.09.2004)

Sofie and I have had a nice day yesterday. We are now officially young guides! The slogan of this year goes as follows: Young guides, get rid of your fancy clothes and start to joggle. We go forward. And back. Jo-jo-jooooo ... The Young Guides are like this! (Lynn, student, 20.09.2004)

Stubborn Sofie today! All questions, suggestions... invariably are followed with a 'no'. She finds that quite funny. (Elisabeth, assistant, 07.10.2004)

Maths test: Point numbers are really hard. Sofie does not respond to questions about point numbers. She thinks she doesn't master it yet, but want to practice more before she can take a test on that matter. Miss Perfect! (Lynn, student, 13.10.2004)

Sofie is concerned about my back and asks how it feels now. What a sweetie she is! (Lynn, student, 22.10.2004)

Our Sofie is a girl of principle, a secret is a secret until we tell the others. (Ilse, assistant, 28.10.2004)

Sofie has worked well with Gertrude. She has almost a melody for her next song. It's really a subject for a teenager. Sofie wants to make it a little longer before revealing it to the class. (Ilse, assistant, 11.10.2004)

During playtime, Ayla and Banu remain inside. They play a game called 'Who is it?' Sofie's a real teaser and always says quite the opposite of what the card says. (Ilse, assistant, 12.06.2005)

Social contact

Sofie gives insight into what she expects from friends. It shows us how she herself contributes in a friendship.

This morning we arrived right in the middle of religion-class. They had to look for things that were not fun when a group did it. Immediately the five children of her group came to her. Sofie wanted to say something. With her spelling card we arrived at 'g'. Beste could guess it. A group is a mess if there is too much gossip! They were really glad they had discovered and understood that Sofie did not like it. (Elisabeth, assistant, 09.09.2004)

Sofie responds to the question: 'What do you do with your friends in class?', as follows: 'learning' and 'writing'. To the question: 'What is important regarding your friends?' 'Listening.' - 'Understanding.' - 'Laughing.' Playtime: Pinar and Bane continue with Sofie: 'Jokes.', 'Comfort.', 'Love.', 'Riding a horse.' Together they try to create a text with the words Sofie gave. (Lynn, student, 11.10.2004)

Classmates tell in a survey about the class relations different things about Sofie. Children know much about what Sofie (dis)likes. There is much information on how Sofie takes part in activities, children describe this in detail. They realize that Sofie is not always participating in the same way. It is clear that 'helping' plays an important part in the relationship with Sofie. Her humour is an important mean to make connection.

Sofie is a nice girl, she does her very best and is good in maths. I would love to work as an assistant of Sofie. I really like to help her. For example, you wipe mucus away, when she coughs. (...) We have to do more lessons and large exams. She usually does the small tests, because she is tired more quickly. (Durim)

Sofie plays a lot with the girls. I find her beautiful. She likes to joke together with the teacher. So, the teacher asks if she is happy and then she says 'no' and laughs. If someone fights, she gets

angry. If something should be said out loud, Sofie can't. But she can be heard with the computer. (Alp)

During the noon we like to play 'teacher' or 'doctor' with Sofie. Aysel or Kader become babies and Sofie is the mum and then I play a doctor. So, then I check the baby's lungs. Sofie shows where her baby has pain. (Banu)

Sofie is a funny girl. She's my best friend. If I wave at her and she says 'no' and I ask her why she says "no", she laughs. She joins us if she can. She's a good painter. When we ask her what colour, she shows the colour she wants and then she looks at us. Sometimes she doesn't cooperate when putting on her coat. In an exercise we say $177 + 367$, then she gets two options. She gives her answer by eye gaze. It is right or wrong. She pays close attention. (Aysel)

If we do a test, we do the whole test. Sofie must do what she can and what she has learned. The rest she will learn later. (...) Sofie is really good at maths, I taught her times tables. (Beste)

Sofie is a good girl, a beautiful girl. If she wasn't so handicapped, she would even be smarter and better. (...) Sofie is very strong. She can do everything well, it goes slow. (Hande)

We have learned about Mother Teresa. I dreamed that Mother Teresa asked me what I wanted and I said I wanted that Sofie could talk. She then bewitched Sofie so she could talk and walk and her hair had changed and was beautiful. I dreamed that she was my sister. [What did she say if she could talk?] Ooh, Ulvi, I am so happy that I can talk now. (Ulvi)

In the evaluation of the sixth grade, the principal and teacher Ellen also think about the contacts with classmates. Adults fear and have doubts about the social contacts. The confrontation with 'normalization' plays a role.

The children have the need to be explicit about the possibilities and limitations of Sofie. How do we call them? How do we handle them? The principal sees Sofie playing the guitar not as a "top performance". It looks like that if she hears support workers talk about it. How fair are we then to other children? (Evaluation 6th grade)

Class group and organization

We take a dream start in the sixth grade. There is a teacher who is consciously choosing for inclusive education. The class is very small, only 14 pupils, it is almost like a big family. Two days later, it all looks different. The two classes of sixth grade are combined in order to split the fourth. Sofie ends up in a classroom with 27 students. It is not an obvious class group with many unpredictable teenagers.

The bus is okay to do. We find our way very easy. The boys in the class were impressed by the accessibility on the bus. This is the first time this morning because in school they have done their best to stand out... (Elisabeth, assistant, 26.05.05)

Ellen is a teacher with little experience, but very demanding in regard to herself. She tries hard to keep the group together and under control.

Miss Ellen asks if we can come on time in class. Now her introduction is disrupted. We try the following: after the first bell we go into the classroom and do not wait in a row. Teacher asks Sofie also to come in time in the morning. If this is not practical to be organised, Rita, talk to the teachers about it? It would be good to make clear appointments. (Ilse, assistant, 29.09.2004)

System using points: beginning of the week everyone gets 4 green dots. If someone does not respect the agreements, he/she loses points. Agreements: 1. I never shout the answer. 2. I look at the teacher. 3. I keep on working on the assignment. 4. I'm done with homework on time. If at the end of the week all four points are still in your possession, you get a bonus point = yellow point. If the class has enough yellow points, they will do something fun with the teacher. If someone has zero green cards, he/she does extra work. Teacher Ellen says that the assistants can also take green points from Sofie because she can't always see how Sofie works. (The green points are in the front satchel bag.) (Lynn, student, 15.11.2004)

The principal tries to support Ellen and relieves her of additional tasks. She appoints the remedial teachers Sanne and Chantal to work with her group more often, so Ellen is able to divide the group in two smaller groups several times a week. In the meantime, the principal talks several times with the class.

Playtime: The principal calls Sofie. New rules about noon: Sofie leaves the classroom at 11.15. Mon: Miss Sanne - Tue: Miss Chantal - Thu: Miss Sanne and Fri: Miss Chantal. When the director asked her what she thinks about it, Sofie answered: 'It's a good idea'. (Ilse, assistant, 18.10.2004)

Trees explains to the class that Miss Ellen was ill because she's so disappointed. The class becomes silent. Sofie, too. Finally, all children have to write the teacher what's on their heart. (Lisa, student, 07.06.2005)

It is the first year that the teacher requires full-time support. Sofie cannot be without support worker one single moment. She sees it as not feasible otherwise. If the assistant cannot be there, she asks Sofie to stay home.

The reason on the absence note may simply be: illness of assistant. (Ellen, teacher, 30.11.2004)

The teacher calls for a solution for the hour on Mondays that Sofie is alone. She found it irresponsible. She asked to report it. (Lisa, student, 13.05.2005)

The teacher looks back with mixed feelings on the past school year. She feels she could not do what was necessary. The class is very difficult; it did not had to do with Sofie alone. In working with Sofie the teacher had difficulty communicating and ensuring her participation.

It was very nice and on my explicit request that Sofie came into my classroom. It was a huge task to involve Sofie in the classroom. Communication with Sofie was a major challenge with the yes/no answering, which also strongly changed after the period in hospital. I often experienced the feeling of failing. It was very intense to work with Sofie and with this class. Sofie could achieve many things, even though the subject matter of the sixth grade was very greatly simplified. It was probably required in this group of teenagers to provide pupils with a much more experienced teacher. It was after a while no longer feasible to continue to foresee adapted tests for Sofie, which I regarded as my duty. I have and keep a lot of appreciation for Sofie and what she does at school. (Ellen, teacher, evaluation, June 2005)

Planning of therapy

By adding together the two classes the class schedule changes dramatically. At that moment it's no longer possible to slide in the working arrangements of the therapists. We don't succeed to fix individual goals and therapy in a manner that Sofie and the classroom will not be disturbed by it.

Barbara arrives after playtime and explains me further the new lifting techniques. It's a bit weird, it's almost 11 o'clock and we really haven't been in class yet. (Lynn, student, 06.09.2004)

Gymnastics: Because of the shift of classes, the gymnastic classes are moved before playtime. Speech therapy falls now in the middle of her math class. (Elisabeth, assistant, 09.09.2004)

Trees had to adapt the swim grid. The sixth grade goes to swim every 14 days, starting from October 6 on Tuesday morning between 10 and 11 o'clock. This is the moment Susan comes. So, we will have to reconsider some things. The rest of the timetable will probably also be adjusted. (Lynn, student, 20.09.2004)

Sofie herself finds it annoying to miss a lesson or to interrupt lessons because of therapy.

As Barbara only comes at 11:10 AM, Sofie can follow math class. She is happy that she can make a few more exercises. If we go out of class, Sofie drops her head. The teacher sees it and says she will soon come and that she already made enough exercises. (Lynn, student, 13.09.2004)

Maths: After Barbara, we drop by teacher Sanne. Half the class is working with percentages. Sofie missed instruction time. She does not want to exercise more. (Lynn, student, 22.11.2004)

Miss Ellen finds it difficult when Sofie leaves or enters the classroom. This breaks always the rhythm of the class.

Barbara asks if she can come between 14:25 and 14:45? I look at the schedule and will let her know. It is just before and just after playtime. Teacher Ellen doesn't like it when Sofie must leave early and come back in class too late. (Lynn, student, 11.10.2004)

Project work

Ellen works with themes within the classroom. The class is divided work in small groups and works for a month with one subject. The pupils help to define the subject. They are challenged in various ways to bring in information themselves. There is always a visit attached to each project. The group can find out what could be the contribution by Sofie. At home she likes to be busy with collecting material on this theme. She's very motivated. This working method works well with Sofie and the other children and is very much focused on cooperation and participation.

Sofie gathers her documentation of the universe in the blue folder. Please leave it in the satchel! Thanks! This evening we have also looked on a fine website about the moon. (Rita, mother, 07.09.2004)

Geography: We worked further on the presentation about the planet Jupiter - Sofie decides who says what. This is real teamwork! (Ilse, assistant, 15.09.2004)

Planetarium: Sofie had expected something more spectacular and found what was told not that interesting. Most of it she already knew. (Lynn, student, 19.09.2004)

Test about space: Teacher Ellen even had a test made for Sofie. It was even a good test. First, Sofie had to decide: which came first? Plane or helicopter? Zeppelin or landing on the moon? Afterwards she had some questions to answer with true or false. Sofie herself studied the test very good, it went so smoothly. (Elisabeth, assistant, 23.09.2004)

Sofie will make the presentation of her planet Jupiter together with Derya, Ayla and Beste. Sophie starts off with 'Jupiter' on her Big Mack. Beste, Banu and Ayla introduce their planet. They do this all alone. (Lynn, student, 27.09.2004)

Illness dominates in the sixth grade

From January to April Sofie is very ill. She stays in a hospital for six weeks and is home for some time afterwards to recover from a life-threatening pneumonia. This creates a break in the sixth grade. Sofie misses very much and her health requires absolute priority.

To teachers Wim, Sanne, Chantal, Thomas, Rita
To the principal
But definitely... To all girls and boys from the sixth grade and Teacher Ellen

Sofie is taken to hospital.
She has a very severe pneumonia and is very ill.
The doctors and nurses want to help Sofie as good as possible.
They monitor her very closely: this is called "intensive care".
Her parents even cannot visit much.
So, we thought it would be nice to send you an e-mail about how it is with Sofie.

For the moment Sofie sleeps day and night.
She is in a big bed with lots of machines around her.
They also make sure that Sofie gets her medicine.
There is a machine that breathes in place of Sofie.
Thus, Sofie can get better.
In her room there are reflective stars stickers on the ceiling.
Cards and pictures of Sofie from home are hanging on the window beside her.
Thus, Sofie can get better.

Mom and dad spend a lot of time with her.
They tell Sofie what is happening and that many people want her to get better.
Every time her mother tells of 'tests', Sofie's blood pressure is going up.
When her dad talks about 'French', we see Sofie's toes curl.
Mom and dad give her lots of hugs and kisses.
We know that Sofie's trying hard to heal.

Sofie is very strong.
The doctors see that Sofie is recovering, her blood pressure rises, the amount of oxygen in her blood increases, her fever is gone, the dirty little animals in her lungs diminish, she begins to cough on her own...
She can now sleep a little less.
Then she starts to 'talk' with us: she blinks her eyes when she says 'yes'.
She shows us that she hears us.
Then she goes back to sleep.

Sofie is bit by bit getting better!
It will probably take quite some time before she wakes up, and before she can return to school.
In the meantime, we keep you up to date.

With many greetings,
Sofie (we will read her this e-mail)
Toon and Rita
Ilse, Lynn, Lisa, Anke and Elisabeth

Returning to regular life is not easy

Sofie returns to class in early May. She gets tired very fast and repeatedly falls asleep in class. Sofie has still problems with breathing. She cannot just pick up the thread which dropped before Christmas. During recovery we see very unclear communication and increased mucus production. This affects the social relationships with peers.

Sofie is starting very slowly. She gets tired much faster and it still can't be requested a lot from her at present. The adjustments can often happen at the moment. Sofie has a lot more mucus than before. She focuses much more on her breathing. This makes much more noise. (Team report, 27.04.2005)

Sofie now has more mucus. This is probably because the diameter of the tube in her trachea is much bigger. The mucus also flies much further. It influences her social relationships. It is the first time that there are really comments from other children. Sofie hears herself breathing much louder than before, this sometimes distracts her. (Team report, 18.05.2005)

Communication with Sofie went for none of us easily: the yes and no were not as clear as before. This made it not easy in relation to other children. The importance of communication only grows when Sofie and her peers get older. That makes it not easy. (Evaluation, 6th grade)

Preparing and looking forward to next year

Sofie is in the process of choosing a secondary school and has a great share in it. Her interests play an important role in the choice of school. She visits three schools. Schools with many children from her neighbourhood are considered as a big advantage. Sofie's parents opt for general education with a broad content base. They always make the first contact and inform principals about their choice for inclusive education. It is important that the school is open to their daughter and to the current way of working. Sofie is concerned in her admission requirements and whether the school wants to work with her.

Concerning the school choice, Sofie wants to go to Don Bosco, and is quite sure of herself. I explained her that we will visit different schools and that it is best to choose only at the end. She found that an acceptable idea. (Lynn, student, 28.09.2005)

Secondary: Sofie has top three concerning school choice:

1 / Don Bosco

2/ St. Paul

3/ Erasmus

This is what I was allowed to write down after the conversation between the speech therapist and Sofie. (Lynn, student, 09.11.2004)

After the playtime Sofie says: 'I do not understand, mother'. She does not understand why her mother today has to visit two other schools. She is afraid she will not be able to go to Don Bosco. (Lynn, student, 06.12.2004)

Sofie is busy with attestation and a certificate. This subject is addressed in the classroom. Lynn and Rita have tried to frame it. If she has any questions about it, we can try to ask for more information to the principal of the school where she will go to. Perhaps they can reassure her? (Team report 27.04.2005)

Sofie follows the preparatory work which all children in the class get concerning orientation towards secondary education. Miss Ellen talks about what changes secondary education entail. Most children opt for a vocational training. We visit several schools in Ghent.

Teacher explains that next year the pupils will have different teacher for each subject. She does this by going through all courses of the day and telling that each course would be given by a different teacher. (Elisabeth, assistant, 30.11.2004)

The transition to secondary school is from the beginning a hot topic. Classmates reflect on their choice and talk about it with Sofie. There is continuing uncertainty in each of them.

At noon Beste and Kader come to chat. The talk is about next year and what school they want to go. A little later everything is decided. Beste and Kader will arrange and sort things out, so Sofie can go with them to the Lucerna college. Then they sit together in class - that would be super. Great to see! (Lynn, student, 07.09.2004)

There are a few points of attention when going into secondary school. There is an ambulatory nurse who will do the care at noon and four o'clock. This should no longer be done by the support workers. In advance there's a lot of puzzling about the program for therapy: everything will be placed in Sofie's school curriculum with additional emphasis on communication, computer and Adremo.

Care: Sofie has indicated that she does not like it that different people help with her care. In the past, Sofie already indicated that the care would rather not be done by 'strange' people or assistants. When the nurse comes to replace Ilse, it goes very well. Rita asked if there is a possibility that every day someone comes from the district health centre. In the meeting with school, we also want to introduce this. We take this with us into the secondary. (Team report 10.11.2004)

We make an inventory of all individual moments Sofie really needs. Susan thinks for example to provide speech therapy for three hours with the intention to really work intensive on communication. (Team report, 18.05.2005)

There is need for thorough preparation facing secondary school. There are several contacts with the principal. Teachers are being informed about who Sofie is and what the expectations for education are. Sofie and her family can start their vacation with peace of mind, and leave the primary school behind.

Teachers can still sit together for a moment with Rita and the assistants before the school year starts. This is possible after the staff meeting on Tuesday 30/08. The exact hour is not yet clear.

Sofie will start in her first year with exception for a number of subjects. The lessons that she doesn't have to follow create some space for therapy. We have 4 hours of Latin, 2 hours of Technological training, 2 hours of Physical Education, and 2 hours of Art work. That makes a total of 10 hours for Sofie to have therapy. In September Sofie can 'taste' all courses and at the end of September we decide which courses she drops. Then it is easier to make a choice, then we all know what it is about.

Therapy:

3 hours Communication from Susan

1 hour spelling from Marjolein

3 turns physical therapy - driving the electric wheelchair

Spaces:

- There is a spacious room with a table and a sink. Sofie can also receive therapy there. This is close to the classes. Here the Adremo can be placed and be recharged.

- Sofie is to arrive in a class of 24 children. This is the average. The smallest classes do not have enough space for her.

- The Adremo can be practised in the changing rooms for the girls. Only the banks should be pushed aside.

Contact persons and communication:

This is the class teacher of Sofie. He/she can then put everything on the small team councils, which takes place every Monday at a fixed time. You can also easily communicate by email. There is also four times a year a big meeting. Then all teachers are together from 16 until 18 o'clock. (evaluation 6th grade)

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Chapter 6

**Swimming is never without risk.
Opening up on learning through activism
and research.⁵**

⁵ Based on De Schauwer, E., & Van Hove, G. (2011). Swimming is never without risk. Opening up on learning through activism and research. *Qualitative Inquiry*, 17(2), 224-232.



(Bill Viola, Taking the plunge, 2008)

Abstract

This paper examines my own becoming as Elisabeth and as a researcher. It is about working as a support worker, coaching teams that are trying to realize inclusive education for a child, and my PhD-process, which relies on these practices. My intention here is to unfold several aspects, blockages, possibilities, and tensions that can make sense of my messy struggle. The never-ending learning through working with people, listening to their stories, and taking responsibility are important ingredients of my engagement. It is necessary to provide insights and justify my multiple positions in order to avoid falling into a narcissistic trap. In doing so, I will seek help from Levinas and in concepts of Deleuze and Guattari to (re-)construct my own understanding.

6.1. Some signposts along the way

Writing this article meant looking back at the last 10 years of my life - a long (and for me: very meaningful) period. These reflections are about my positions as a subject during this work: Elisabeth - advocate - partner - pedagogue - mother - researcher and many more. It is a personal story told from my own point of view. It has to do with me, the things I do and what I learn(ed). It also has to do with other people, their 'gifts', the doubts and challenges they shared. It is a difficult exercise to do justice to everything and everyone. I have imposed a chronology onto events which usually seemed to occur together or only became visible afterwards. The story is not as linear as I will portray it. Almost everything I came across seemed like a coincidence at the time. There were no planned and progressive stages. Some things developed very gradually, while others happened simultaneously. Some I was aware of, others really took place on a subconscious, intuitive level. The further I get, the more strongly I am convinced: I am a subject of lack (Lather, 2008). I will never get it right or complete. My becoming and the processes I engage with are complex, ungraspable as a 'whole' and ongoing. Let's dive in somewhere 'in the middle', because things do not begin to live except in the middle (Deleuze & Parnet, 2007, p. 55).

6.2. Feeling currents in the water

Towards the end of my master's training, two important seeds were planted. They felt like two confrontations with different relationships in working with and looking at people (with a disability). I felt very attracted. I wanted to try it and make it part of myself. At the same time it frightened me: could I do this? It looked like troubled water, but people along the path pulled me in and I was also curious - so I followed. I came to understand these encounters with the Other as my lines of flight. They made small ruptures in my everyday habits of thought and initiated minor dissident flows (Roy, 2003 as cited in Gough, 2006, p. 63)

During my master's I took part in two intensive programs on inclusive education. The ideas bit deep into me. Seeking different ways of education for children with a disability and being introduced to 'real' persons (and not to their disabilities) intrigued me. I heard a mother and a teacher talk about a boy they lived/worked with; his story touched me greatly: the child, the parent, and their perspectives on everyday education. The shared searching of the mother and the teacher was impressive. I wanted to know the boy, his family, and the school. It happened: I met Kobe, a boy I was going to work with as a personal support for 3 years.

Around the same period, I got involved with strong men and women in the Flemish self advocacy movement. I saw people angry, banging their fist on the table. They were listening to each other and exchanging stories about their lived and very concrete experiences. The discovery that those men and women had the ability to speak about who they were and what they wanted was an eye-opener. People could be very clear about what support felt like 'good' support and that only the receiving person can decide on that. It was not about me and my 'good' intentions. They talked about a lot of useless support, support they didn't ask for, support that people are not given in order to prove that they cannot do it themselves, etc. Support, I learned, really has to make the person feel supported, otherwise it has little worth. I felt like Alice in Wonderland, but became active and still work as a voluntary advisor there.

In this story of encounters with the Other, Levinas and his radical other-centeredness is very helpful. The Other is crucial, the only way to be able to think and talk about me. Safstrom (1999, p. 227) sees that: "The Other gives the subject meaning. The meaningful subject, the self, becomes a consequence of the relationship to the Other – a relation which does not strive for the coinciding with oneself (Levinas, 1994, p. 118). Otherness becomes constituting for the subject's being." This way of working has serious consequences. "It is only when I come to see that the meaning of my being is in being 'hostage' for the Other that I can realize what I am" (Chinnery, 2003, p. 8). The appeal of the Other is so strong that I cannot do other than follow and serve. It demands a response that cannot be prepared beforehand, I have to surrender. The relation with the Other is an ethical relationship, where I am no longer in control. "Levinas

proposes that the ethical relation is modulated through the way in which I welcomes the Other, receives from the Other and is taught by the Other. (...) He describes welcoming the Other as the self's capacity to learn from the Other as a teacher" (Todd, 2008, p. 171). In the two situations described above, I experienced intensively how powerful the appeal of the Other is and how much wisdom you receive in actively listening to it.

6.3. Swimming without a proper stroke: working as a personal assistant of Sofie

I spent 7 years as a personal assistant together with Sofie. I followed her through primary school and supported her two (later one) days a week in class, but also at home and during leisure activities and holidays. I was confronted with so many different contexts and got to experience many different things that went together with Sofie as a (disabled) child: standing up at night to check on her, seeing fear in the eyes of a teacher when Sofie came into the class, strange fevers, buying an adapted car, looking for appropriate communication devices, not being able to understand what she was saying and many others.

I've learned a lot from the personal contact with Sofie. Because of the intensity of support Sofie needed, I got very close. We had to build on a relationship of trust to work together. It helped to know who Sofie was when I learned to see her as the daughter of Rita and Toon, the pupil of the class of Mr Wim, the friend of Aysel, and so much more. Radical openness brought me closer to the individual person, Sofie, with all her possibilities and difficulties and in connection with the people who loved her. Her appeal was very strong and demanding, so I could not help but take responsibility. It was inescapable. There were no conditions attached, no receipts or reciprocating services were asked (Isarin, 2005). I was committed because she challenged me and I wanted to respond. Searching for how Sofie could participate and find her place among other people was my way to fulfil my obligation towards her.

From the beginning, we started from the 'voice' of Sofie. She had an opinion. What did she want? Just ask her! When she took the initiative, even in very small ways, we followed her. We wanted to give her a certain feeling of choice and 'control' over her support and in what happened with her in the class and outside. "To recognize the Other is to give. But it is to give to the master, to the lord, to him whom one approaches as You in a dimension of height" (Robbins, 1999 as cited in Simon, 2003, p. 55). This asymmetry opened a 'space' where the two of us could both learn and find ourselves in exposure and vulnerability to each other. "It is the orientation to the Other which affirms her independence, her height, her foreignness" (Todd, 2008, p. 180).

Often, but especially in the beginning, I didn't have a clue about what I could do, how Sofie could learn, and how we should adapt her learning material. I did not want to feel like a 'professional'. I wanted to distance myself from that dirty, uncomfortable word. I felt I couldn't meet the expectations that went with the 'job'. I was not a real teacher and yet I was working in a classroom. I didn't have a lot of expertise about children with serious disabilities, and with what I had I could not 'help' a child like Sofie to participate in a regular class. The only time I had seen such a girl was in a class with four children listening to Enya and tasting fruit to learn the difference between sour and sweet. I had to leave my references about schooling behind. "Such an ethics, informed by Levinas and not in itself a theory, but rather a reorientation to human subjectivity has as its core an absolute responsibility to the Other because of one's own inadequacy in the face of the demand of the Other" (Critchley, 2007 as cited in Allan, 2009, p. 7). What I could offer was very little except my commitment and my energy. I wanted to be seen as ordinary and approachable in order to get solidarity and shared interests from her, the teacher, the other children, the support workers, and her parents.

We were working a lot through trial and error, interpreting situations and moments. I had to learn to see with new eyes. I became more at ease when I discovered a new lexicon. Talking about 'response' became talking about the gestures and body language of Sofie with which I was familiar. Talking about 'participation' was a continuous search: she was involved in the classroom but not at every moment nor in the same manner as other pupils. Listening to and observing her parents, we

learned to see through positive spectacles in the class. We were thinking and talking in terms of opportunities and possibilities for Sofie to participate and engage in 'real' contexts. That does not mean that difficulties did not exist, but they were not in the front seat. We learned that for every problem there exists a solution - one which you don't find in advance but often at the time or through a lot of searching. In working this way, we saw Sofie (and our own confidence) grow and change. That was very important in reassuring us that our collaborative work was appropriate. However, each time we thought we had found something, Sofie asked otherwise or the circumstances changed. We constantly had to be 'awake', tune into her desires and adapt ourselves and our way of working. "Responsibility is about surrender and openness to the other, about saying 'yes' to the otherness of the other, and about suffering through anxious situations not of our own making, but to which we are nonetheless called to respond" (Chinnery, 2003, p. 7).

I've learned a lot about giving support. In working with Sofie, I had to 'listen' and watch her very carefully and minutely in order to know my position and what I could do. Safstrom (2003, p. 28) understands it: "It is the individual uniqueness of the student that exists beyond his/her institutional position as student, which teachers [support workers] meet - and defend- in their answerability and self-questioning: (...) Have I the right to teach [support]? (...) It is continuously answered within the teaching that actually takes place, within the dialogue where response to the other becomes possible." I had to allow Sofie's guidance. "I am approached by the Other prior to any choice of thought, so that the priority of the self is challenged by the priority of the Other, towards whom I move and through whose address I am called into being as one responsible" (Strahn, 2007, p. 422). Levinas (1981) speaks of passivity as being affected, touched and sensitive to the Other. What does Sofie want? How does she want it? When does she want me close? When do I have to keep my distance in order to let other people (teacher, classmates) take their responsibility? I had to earn the right to work with her over and over again.

We practised a lot in creating bridges and supporting connections. Sofie needed intensive support, but it was not the support workers who had to be 'best friends' with Sofie. A very important part of our 'job' was

helping to create ways of interaction, cooperation, and connection between Sofie, the teacher, and other children. We realised that the interactions and relationships which Sofie had with people in her surroundings determined how she was present and how people viewed her contribution. Sofie's parents were guiding forces in this group of people who worked, lived, played, and interacted with her. When I made my application for the job as personal assistant, Sofie's mother was very clear. The cooperation between Sofie, her other support worker, and the teacher was working really well. If I couldn't fit it with that, my help was not required. I felt daunted, but it helped to know my place in the whole context of Sofie.

Together with Sofie and her parents, I met a close network of people around them. The collaboration and intimate connections with Sofie, her parents, the teacher, peers and the other personal assistant was very intense. We sat a lot together with wine and food – formally and informally – we phoned and mailed, we had daily written correspondence about what happened in class, we discussed new and better adaptations. We were thinking and practicing in terms of opportunities and possibilities for the participation and engagement of Sofie in 'real' contexts. Engaging in a pedagogical relationship is "learning with, about and from others that could not have been specified in advance" (Biesta, 2003, p. 65).

6.4. Another swimsuit: coaching teams around children in inclusive education

While I was working for Sofie, I met other children and parents who were looking for support with their situation of inclusive education. It helped me to broaden and deepen my experiences and praxis by transferring to other contexts with other children, while not in the position of acting directly myself in the class. I now also realize – looking back – that indignation is an important facilitator in my work. I was often (very) angry when I heard about the injustice children and parents

suffered in their fight for inclusive education. Being an ally and actively standing in the wind with them was the only thing I could offer.

I cannot relate every story of every child. I can only give some flavour of the precious moments that influenced my way of thinking and working in coaching teams.

Charlie left a small village school after 8 years in the same class group. He finished his 6th year of primary school in a show the class produced themselves. Every child was pictured there as classmates understood him/her. Charlie that evening was very 'awake', very focussed on what was happening and constantly aware of his own contribution and at the same time connected with what the others were doing. His support worker was not with him. The other children had, during their preparation, figured out together how they could stand by him and help when it was necessary. Charlie himself made sure that he wasn't forgotten by yelling, waving his arms or pulling one of his mates towards him. He was clearly brought on stage as a Don Juan with very fine humour and able to play with language. During his moment on stage, Charlie and his wheelchair were an integral part of the dance act. Every piece of the chair and of Charlie's body was used in the performance. He was in the middle, enjoying himself tremendously, focusing very hard on doing everything right.

We put a lot of effort into getting a place for Lily at the same school where she had attended kindergarten, which was only one street away from her house. Her parents were asked to explain and justify their choice to continue her inclusion process and we had the opportunity to answer all the school's questions concerning class practice. After several meetings with and without us, the school made their decision and the headmaster phoned to say: "No, we will not do it. In the end, it boils down to: we are too scared." Lily's mum and I started to visit other schools. We saw 7 schools in all, of which 2 decided to give it a chance. In the car coming home from one of the schools, Lily's mum said: "I feel like I am in a shop window with my daughter. I never got to do this with my other girl who is 'normally' developing. I made my choices and that was that. Most of the time they were glad that I came. Now, with Lily, it's different. I have to show them everything of her and myself. I have to make a good impression, be sure of what I am doing, and defend her education but be always understanding to their ideas and problems. Everybody thinks he knows what is best for her. Her and our lives become the common good." [my translation from the Dutch]

Ruby's teacher is on my phone. She has to explain to her colleagues why she wants Ruby to stay with her classmates, even though she did not reach the standard for passing the first year of primary school. "Can you help me to put all the arguments together? I know that the social relationships are very important, but can you give me some arguments to back this up?" We talk about Ruby's wellbeing in the group and her individual educational plan.

When William was about to start his third year of secondary education, a lot of teachers had questions concerning the practical sessions for vocational subjects. Would William do what they expected of him? In the workplace they would not be in a position to check on him all the time. What if he ran away? What if he drank poison? He would be working with real tools. What if he wounded somebody? They were open to ideas but generally very negative about the prospect of teaching William. His mother was fielding a lot of questions and together we tried to tackle each

argument. His father remained very quiet for a long time but then said: "I understand a lot of your questions. You do not know William. You do not know how to handle children with Down's syndrome. Fourteen years ago, I had the same problem, but nobody asked me if I wanted to do it, I just had to try and make the most of it." [my translation from the Dutch]

I want now to turn to Levinas to discuss some elements that were very important for my position in working in these kinds of situations. I do so in the strong belief that it is essential to give people the authentic sense that they are not alone, to listen to their stories carefully and spend time with them without expecting recognition. Our fates are intertwined, for a brief moment or as long as they want. In supporting, interacting, fighting, and working together, we are made most aware of the threads of responsibility for the (education of the) child which bind us. This proximity is situated on the level of sensibilities between humans and therefore cannot be pinned down to fixed structures and predefined tasks. I can be very close and I can feel touched, but what it is that has passed between us is often beyond my capacity to comprehend. I could never fully grasp or take on the emotional bond of a parent towards their child. I can never feel how a child with a disability feels part of a regular classroom. I do not have to try to overcome the distance of the difference. "The substitution of inspiration involves carrying the Other, as other, right in my very interiority, without becoming one with the other" (Peperzak, 1997 as cited in Joldersma, 2008, p. 50).

A lot of my work came down to listening very carefully. There is an appeal from the Other that I can sense. The Other can be a child, a parent, a teacher, or another professional involved in the process of inclusive education. Listening to the Other requires a relationship of respect and obligation. It needs a strong commitment to dialogue where response to the Other becomes possible and I cannot claim to know and be able to explicate for the Other. Rinaldi (2006, p. 65) speaks about "listening as sensitivity to the patterns that connect, to that which connects us to others; abandoning ourselves to the conviction that our understanding and our own being are but small parts of a broader, integrated knowledge that holds the universe together." I am trying to listen to the Other from his/her own position. "The listening aspect of learning from a teacher is not only a good strategy, but points to the very subjectivity of being human, to evidence of the 'I' in terms of 'Here I am!'" (Joldersma, 2008, p. 53).

Searching for encounter and relation means opening up oneself to the Other and being ready to respond. It is about curiosity, communication and being able to surrender. Knowing about me and my personal situation and showing genuine interest allowed children and parents to show kindness and concern and to engage in an ordinary human relationship. Todd (2003, p. 41) puts this in Levinasian terms: "When I show love, generosity and affection, I do so to ensure that further openness and communication are possible and that the other is given the space and time to become themselves responsive/ responsible subjects." Openness also requires flexibility. I cannot deliver a standard package of services. As a result of listening to and negotiating about what people want me to do; I can do many different things, from babysitting to going to file a complaint at the Ministry of Education, and from talking with the teacher about using a calculator during maths to coordinating the support of the child during their school career.

This degree of openness also brings risk: "It is the exposure to the other in which a risk is taken, a risk to suffer without reason, for nothing. (...) In order to enter into an ethical relation with the student, the risk embedded in the saying is an inevitable one. It is an uncertainty and vulnerability of uncovering oneself for the student. The risk (...) makes the welcoming of the other possible" (Safstrom, 2003, pp. 25-26). In being a *compagnon-de-route* for children and parents, you have to give up your 'safe' position as the professional. You have to be prepared to fight and get your hands dirty. You share moments when they feel pride when success has been achieved. You also cry when people are disappointed, damaged or deprived of their rights. You cannot shut out the pain people face when society and education puts the emphasis on 'normality'. As a pedagogue in inclusive education, I feel affinity with jazz musicians, who, as Chinnery notes (2003, p. 13): "Engage in rigorous study and practice in order to build up their memory of repertoires, then, at the moment of performance, they must suspend deliberation and abandon the known in order to embrace risk and vulnerability. It is about the capacity to vulnerability and exposure to the Other, to the pains and pleasures of human life."

In working together and actively doing and being involved with children and inclusive education, my need to search for meaning only grew. I felt often as if I were walking a tightrope, but the process delivered me penetrating encounters and experiences with great potential. Sometimes it went together with anger and frustration. Sometimes I could enjoy intensely goose bump moments when children were able to participate and belong in their class. Below, I want to make a connection between this Levinasian encounter with the Other and the desire of Deleuze.

'Desire' is about experimenting with "dare to become all that you cannot be" (Massumi, 1992 as cited in O'Shea 2002, p. 930). Desire and belief steer my rhizomatic way of thinking. "Deleuze and Guattari's notion of the rhizome enables us to concentrate on a mobile, disjunctive relational self which evades oppression in avoiding 'being' in any static and essentialist sense" (Linstead & Pullen, 2006, p. 1295). The rhizome is always relational, it is about connecting and becoming - "the rhizome is uniquely alliance... the rhizome is conjunction" (Deleuze & Guattari, 1987, p. 25). It is about continuously being open and answering possibilities of being affected by difference. The rhizome can be seen as "productive, creating lines of flight and other futures" (Diedrich, 2005, pp. 238-239). By moving in a rhizomatic way and getting involved in processes of (de)territorialisation, you are challenged all the time to become somebody other than who you are, what you are. "The rhizome is made only of lines: lines of segmentarity and stratification as its dimensions, and the line of flight or deterritorialization as the maximum dimension after which the multiplicity undergoes metamorphosis, changes in nature" (Deleuze & Guattari, 1987, p. 21).

Desire pushes you and leads you to new and positive futures. On the back of desire you fly along rhizomes away from a stable and universal identification as a 'pedagogue', 'support worker', 'activist', 'researcher', 'mother', 'friend', and 'academic'. You discover always new connections and possibilities. You construct and reconstruct yourself over and over. You do not have to look for these processes very hard, they just happen. Desire gives you endless opportunities to keep in movement and continuously become by crossing borders, dichotomies, and categories. You are privileged to meet a multiplicity of differences. "Productive desire is a power, a passion that moves one towards something new, the

other. Desire does not lack anything; it does not lack its object. It is, rather, the subject that is missing in desire or desire that lacks a fixed subject; there is no fixed subject unless there is repression" (Deleuze & Guattari, 2004, p. 26).

In supporting children with a disability and working in education, the perspective of desire has serious consequences for ourselves and the children we work with. It means we cannot focus on 'individualism' and 'autonomy' as ultimate or even desirable outcomes for a human being. As Gibson (2006, p. 190) points out: "The goal of independence limits desire and the appreciation of connectivity. It reinforces disability as limitation rather than possibility and thus may contribute to legitimizing the repressive systems that exclude disabled people." She pleads for "possibilities in experimenting with various forms of dependency, giving and receiving, expecting nothing and everything."

6.5. Breaking the waves: Becoming Elisabeth – Becoming Researcher

From the very beginning, there was a lot of reflection on what I was doing. For Freire (1970), praxis is about doing and reflecting. I often sat together with Sofie's parents and other support workers to talk about her and our way of working. As an advisor in the self-advocacy movement, the self-advocates and other advisors were very active with their critical support at meetings. Our kitchen table at home was filled with stories brought by my partner from his role as a support worker with one of the children I was following closely. I talked a lot with children, parents, teachers, special educators, and headmasters about education and including children with a disability. We faced a lot of uncertainties, tensions, and feelings of crisis but could support each other in creating new thinking and exchanging different perspectives. We shared the same belief and passion in always looking for possibilities in a positive, non-judgemental way. All this activity was interwoven with my work at the university: I read texts, I had discussions with my supervisor and colleagues, all of whom were involved (though they may not have

known it) in a 'secret army'. I was also working with students. I learned from and with the Other. "Meaning making and knowledge construction occur in this relational activity, in a continuous process of formulation and reformulation, testing and negotiation" (Dahlberg & Moss, 2005, p. 102).

Working as a researcher was really a (very) slow maturation process. I realised that all the things I've learned could be shared with other people. At the same time, the parents of Sofie were doing their best to spread the story of their daughter to show other people what is possible. They did this in their working with other people, in their engagement in events for people with disabilities, and other ways. I also engaged with tacit knowledge in exploring the perspectives of other children, parents, and teachers. I could fall back on this and use it to look at interview material, participant observations, and concrete situations in class. From just wanting to be involved to really getting my head around the theoretical concepts that would help me make sense of the complex reality of children in school was a long, never-ending process.

Several struggles went along with this effort. I had a lot of different material from a lot of different angles, levels, sources, perspectives... It was very messy. What was I going to look at? Where was I going to focus? It took me back and forth between setting up new projects and falling back on my ongoing practice. I really had the feeling that the practice I was involved in was just too close to me. I was very much going with the flow but was not able to find a way of describing it. The process caused me to dig in and out of several dark tunnels and come up against a lot of dead ends. I could not arrive at a real sense of what my PhD would be about and what would (not) be part of it. My process as a researcher was constructed through contemporaneous advances, choices, standstills, and retreats that took me in many directions. It took a lot of energy to find concepts that could help me to make sense of and re-think what I had experienced in working with children, parents, and schools.

I struggled in all my writing and talking to find the appropriate words which would open up potentialities rather than close them down the whole time. Working with children with serious communication difficulties was one of my first attempts to identify a group of children

that I would like to work with but that was not recognized as a DSM IV label. This obligation to think outside of categories and disabilities can make my work very broad but also very vague. On the other hand, I could never totally escape the difficulties the children experienced or it would look as if I didn't want to recognize them. The struggle became only worse as I went further. I constantly had to be alert, correct myself, be creative, and experiment. Words sometimes oblige us to write what we do not intend. I had to accept that I could not bring everything to the table, that I could not make visible what was inscribed for years in affects, "as forces of desire continuously flowing and making connections within and between machines" (Tamboukou, 2003, p. 216).

Continuing to practice as a support worker and coach confronted me with time. I needed lots and lots of practice before I could begin to make any sense of difference and how it operates in relationships between people. I always wanted to see what was behind the next corner and kept on searching for connections and new assemblages with other people, new ideas and different contexts. It took a lot of time before I could write and before I found suitable concepts with which to work that could really cope with the complexity of the situations. The proximity I experienced in the situations paralysed my ability to write about them. I needed to feel distance before I was able to discern more critically, taking into account different experiences, perspectives and thoughts.

Another struggle had to do with a fear of exploiting people, misgivings about a kind of voyeurism. This struggle was a matter of keeping my integrity. We were working for each other: some children taught me a lot of things and I did everything that was possible to support them. That seemed like a fair deal. Could I now change the deal and do other things with all the wisdom they had brought to me? My strong focus on micro situations made me, the children, their families, teachers and support workers very visible and vulnerable. I was afraid of not being understood: would other people be interested in learning from stories of children and a lot of different perspectives? Would I be able to explain who these children were and how they managed to turn my (professional) thinking upside down?

Becoming Elisabeth and a researcher also kept confronting me with legitimating the purpose(s) of my work. "The subject-in-becoming is the one for who "what's the point" is an all-important question" (Braidotti, 2006: 148). I wanted to work through experiences, feelings, intuitions, thoughts etc. I wanted to build on, under and between these. I wanted to learn, out of practice, insights and theoretical concepts that made sense of those experiences. I wanted to present complex, fragmented, and multiple stories and characters. On the one hand you see the uniqueness of each child and situation but on the other hand you see certain blueprints that return again and again. "Ways of speaking and doing become habitual patterns that self-replicate even if in doing so they continually diverge from past repetitions" (Lorraine, 2008, p. 63). Knowing how (not in a technical sense) is more important than knowing what. I wanted to tell about the encounter with the Other in the context of inclusive education. I believe, along with Braidotti (2006) and Allan (2009), that we as academics have to fulfil a political commitment towards the children and parents who are involved and who know very well what it is like to fight for social change in education and society. How can we open up the outside and relate to the world?

6.6. Nightswimming: becoming-minoritarian

When I want to bring all the different layers of my experiences together, the notion of 'becoming-minoritarian' of Deleuze and Guattari can help me to understand how I as a multiple identity am relating to other humans, non-humans and to the world. I can take the freedom to become an 'activist' and 'partner' and 'researcher' and 'mother' all at once and negotiate these different identities in encounter with the Other. If we want to take responsibility and go for social change, we have to enter into the experience of becoming. "When something occurs, the self that awaited it is already dead or the one that would await it has not yet arrived" (Deleuze & Guattari, 1987, p. 198-199).

Becoming is a process where stable identities – majorities – continually create new identities rooted in variable and discontinuous fluxes of living. Multiple identities open up new beginnings, new ways of living

and thinking. Becoming is transforming our relationship to the world. "It opens up space in which it is possible to think about how it might be possible to do things in a different fashion. It is a politics 'whose ethos is a reluctance to govern too much, that minimises codification and maximises debate, that seeks to increase the opportunities for each individual to construct and transform his own view of life' (Rose, 1999, p. 193)" (Dahlberg & Moss, 2005, p. 139). It is about crossing thresholds in a cautious, tentative, experimental but nevertheless irreversible way. "There is a type of cracking that is micrological, like the small imperceptible cracks in a dish" (Deleuze and Guattari, 1987, p. 198). In all the unravelling above, I tried to look in detail at that little 'cracks', being aware that I was only able to describe some.

All becoming is becoming-minoritarian (Deleuze & Guattari, 1987, p. 291). In constant movements, we open up one self in diverse actions, connect with the world, escape the status quo with critical thinking, and enjoy the creative flows along undefined boundaries. These processes happen often very silently, without being noticed. They challenge unity and consensus to acknowledge and accommodate many kinds of difference and change the pre-existing order of society, the way in which we govern and are governed. "They carry the potential to transform the affects, beliefs and political sensibilities of a population in ways that amount to the advent of a new people" (Patton, 2007, p. 11).

Becoming is strictly a matter of deterritorialization (Deleuze & Guattari, 1987, p. 307), moving away from the centre to the periphery, to the limits of what is deemed acceptable in majoritarian norms. Individually and collectively the minors are subverting the dominant majority "by a creation that explodes it from within" (May, 2003, p. 149). Becoming-minoritarian is about resistance, "refusing to let those variations be assimilated to binary categories or their implicit tendencies blocked from unfolding new ways of living" (Lorraine, 2008, p. 68). "Becoming-minoritarian is not and cannot be a state, a station, but must be a process that leaves nothing intact in its wake" (Bensmaia & Curtis Gage, 1993, p. 62).

Becoming-minoritarian "needs an encounter that allows for new relations to be established and new experiments in live to take place" (Marrati

2001 as cited in Pisters, 2007, p. 20). The confrontation with the Other imposes becomings and demands the boundaries to become blurred and breached. Working with people with a disability, I felt the need to decipher who they were to understand them more and better. I wanted to unravel their history and deconstruct the mechanism that sets them apart in our society. I tried everything to overcome difference and create common grounds between people with and without disability. "Difference is supposed to vanish, to be dealt with and to be exceeded in favour of a harmonisation of opinions and stands" (Safstrom, 1999, p. 224). But this does not work. Levinas taught me why not. It is one of the biggest traps in inclusion and inclusive education. I forgot that it is exactly difference that people take into whom they are (becoming). "It is precisely because the You is absolutely other than the I that there is, between the one and the other dialogue" (Levinas, 1998, p. 146). Difference is beautiful and beauty orients and attracts. People go in and out, say yes and no, go back and forth. "If one could possess, grasp and know the Other, it would not be the Other. Possessing, knowing and grasping are synonyms of power (Levinas, 1987, p. 90). (...) Eros is only possible as a relation because there are two. That is why we need both proximity and duality" (Todd, 2003, p. 36). There are always, in encounter with the Other, remains of the Other that stick to you and are irremovable and at the same time we cannot reduce the Other to some version of ourselves. "The other does not fit within my categorization and expectations, my totality and economy, my sameness. The other is a stranger that I welcome in my home" (Joldersma, 2001, p. 182). This reality asks for a deep respect for the otherness of the Other.

We cannot divide the pie, there is no end on the horizon, and everything is endless variation. "To be taught in the encounter with the Other whom I desire is a *perpetual movement of search*, never satisfied and beyond the order of labour and economic exchange" (Strahn, my emphasis, 2007, p. 419). A researcher cannot stand still and does not find a fixed reference point of knowledge. "It stresses the need for a positive ethics. It is an ethics based on the necessity of meeting the challenges of the contemporary transformations with creativity and courage" (Braidotti, 2005, p. 13). We are swimming in a sea full of waves where one idea connects to another, where one person encounters another, where flows

are broken... In these lived experiences, identities are featured by mobility and word and body touch.

It looks like order, but most of the time it is chaos. It looks like a plan, but most of the time it goes together with frustrations and dancing in the dark. But working with children and their families in regular schools it is still exciting. "It expresses not only a sense of social responsibility but also an affect. Hannah Arendt used to call it: love for the world" (Braidotti, 2005, p. 13). At certain moments it makes my blood boil and my heart beat quicker, so I like it. It is about what I am touched by.

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Chapter 7

General discussion

7.1. Becoming

Looking at the different perspectives that are brought together in this thesis, becoming is a central theme. Inclusive education can be considered as a process of becoming for every stakeholder involved and for education itself. Thinking in terms of constant movement creates opportunities to challenge stratification and categorization that try to lock up, close in and narrow down.

From a rhizomatic perspective, our identity is never fully developed or completely fixed. It is constantly developing because expectations, experiences, values, beliefs, opportunities and desires change over time and in interaction with the environment. It challenges organizational linear models of learning, hierarchies of authorities and traditional notions of appropriate educational pathways. It seems to be true that education presents specific end points at different levels and in complicated structures. Deleuze acknowledges and subverts these certainties: "He affirms the possibilities of becoming something else, beyond the avenues, relations, values and meanings that seem to be laid out for us by our biological make-up, our evolutionary heritages, our historical/political/familial allegiances, and the social and cultural structures of civilized living" (Sotirin, 2005, p. 99).

Our identity is in constant becoming –rhizomatic, nomadic, a constant journey with no final destination. We are never still, always relational, always to come, always to connect, it is about AND... AND... AND... "Rethinking difference then involves not establishing a reactive pole of binary opposition between male/female, *[disabled/nondisabled]*, but a multiplicity of possible differences or put another way by Braidotti 'difference as the positivity of differences' (1994, p. 164). These ideas lie at the heart of the nomadic vision of subjectivity which takes into account experiences of oppression, exclusion and marginalization in everyday life and organization. (...) Deleuze and Guattari's notion of the rhizome enabled us to concentrate on a mobile, disjunctive relational self which evades oppression in avoiding 'being' in any static and essentialist sense." (Linstead & Pullen, 2006, p. 1295) Every subject is caught up in multiple,

connective assemblages that are in continuous change. Thinking in terms of connections and assemblages is a useful way to look at the participation of children with a disability in class. It is not only depending on their capacities but also on their possibilities to make alliances. The social networks with other children, teachers and support workers shape their becoming as a pupil, it is situated in a rhizomatic proliferation of connections and temporary points of assemblage. "The nomadic figure is at ease with the fluidity of place and identity in a lifestyle based on the permanence of temporary arrangements and the comfort of contingent foundations" (Braidotti, 2002 in Mc Laughlin & Goodley, 2008, p. 320). All these connections offer the opportunity to create many different assemblages. These connections and organizations of connections are necessary to exist for all of us.

Through becoming a vast space of experimentation and creativity is opened up. This is an idea of experimentation that is something totally different from the idea of experimentation as a lifeless controlling of all parameters as well as working with an expected outcome (Deleuze, 1994). A single event can disturb an established order or set in motion a process, it happens uninvited. Experimentation concerns that which is not yet known, it concerns that which comes about, that which is new and that demands more than recognizing or representing truth. Teachers give insights on this sort of experimentation in their classroom. Teaching is an (endless) search; we re-think learning and take up creative challenges when we work with children, diverse in abilities. In actions and reflection on our actions we look for possibilities, here and now, with our children. Engaging in a pedagogical relationship is "learning with, about and from others that could not have been specified in advance" (Biesta 2003, p. 65).

Paradox of label

Categorization assigns disabled people a stable and firmly fixed identity or label(s) and manages these in clear and straight-forward structures. This provides order through "the standardized values of a community and mediate the experience of individuals" (Douglas, 1966, as cited in Devlieger, 2010, p. 72). "When a label (...) becomes a 'master status', it, like the racial stereotype, becomes 'the lens' through which the labeled

student is viewed" (Veck, 2009, p. 147). That label affects most of their other (social) identities. "When a label of 'special educational needs' or 'learning difficulties' come to define who someone is, a sea of human possibility is veiled into a thick fog" (Veck, 2009, p. 147). When we label and make other, we deny ourselves the chance to know the richness within the Other and we repress the otherness within ourselves (Booth, 2003). On the other hand labels open the way to educational, therapeutic and medical assistance. They give information and explanation for behaviour that is not understood. A diagnosis can diminish feelings of guilt; the child and the parent are understood by their environment. This is the ambiguous way a label works. When families and individuals with disabilities choose to use the label, it does not necessarily mean that they philosophically embrace it. Individuals with disabilities have the right to determine their personal construction of 'normal' without others being judgmental to their choices. Devlieger (2010, p. 73) sees an active and a passive factor to those classifications: "Passive in the sense that we inherit and more importantly live them, and need them, as without them, the world is not intelligible; active in the sense that they are constructed, that is, they are subject to change." Many individuals with disabilities embrace their disabled image, or 'crippled' bodies (Charlton, 1988). It is their choice in how they view themselves, and they can create their own individual definition of success (Philips, 1993).

Becoming as tactics of resistance.

Becoming is a process that resists categorization, it involves a continual state of motion between elements or assemblages. We can see parents, individually and connected in movements, protest against the dominant discourses used by professionals and society to organize the care and education systems for their children. The expertise of the parents and the multiple identities of the children is swopped under the table. These are those processes that make the children end up in the special circuit, a circuit where because of their special needs they are seen as requiring a different 'treatment' than their non-disabled peers and where they have to work to compensate their deficits before they are 'ready' and may participate. Connor (2008) points out that examination of special education classes reveals a disproportional number of Black and Latino students have been identified as disabled and placed in segregated

settings. "Participants understand the limitations of the learning disability label as implying a global deficit, realizing it is actually about the context of school demands; the over-representation of students of colour and the different impact of the learning disability label in terms of social class; the widespread biases inherent in high-stakes testing; the coercive aspects of special education, such as parents being manipulated to accept the disability label and students not understanding the consequences of an individual educational plan diploma; and the existence of White privilege, evident in social class structures (including schools) that create the basis for economic 'success'. In addition, by using counter-assertions to expectations placed upon them because of their positionality, participants also reveal an awareness of their situatedness. Furthermore, they sometimes counteract influences and expectations by 'pushing back'." (Connor, 2008, p. 365).

Resistance can show itself with many faces. Freire (1970) talks about the 'culture of Silence' in which dominated individuals lose the means by which to critically respond to the culture that is forced on them by a dominant culture. Not everyone is ready to stand up. We need people who are in front, pioneers. Resistance starts with conscientization. "This is a form of resistance that emphasizes social consciousness at micro and macro political levels. Conscientization is literally learning to perceive social, political and economic contradictions, and to take action against the oppressive elements of reality (Freire, 1970). It is a combination of collective reflection and action that occurs at both micro and macro levels of society. (...) This conscientization achieved solidarity and community (Gabel & Peters, 2004, p. 595).

We see some fathers/mothers stand up, revolt and take on the fight. Lorraine (2008, p. 72) writes: "Resistant identities as identities in process – they create new identities rooted in fluxes of living that continually vary from the dominant norm, refusing to let those variations be assimilated to binary categories or their implicit tendencies blocked from unfolding new ways of living." In the stories of parents we often hear a plead to see and work with the capacities of the child and an on-going struggle against stratification. In wanting inclusive education for their son/daughter with a disability parents think strategically: finding (important) allies, networking with people who can support and

avoiding conflicts with persons and agencies that they want to be on their side. They balance the whole time between listening to and confirm the people and actions around their child and at the same time, very silently, push the process in the direction they want to go together with their child.

Resistance is offering a way to understand the complex relationships and negotiations around disability on an individual and collective level. "While the strong social model has not recognized individual agency, resistance theory recognizes agency in the sense that individual resistance operates across the individual and collective levels and is enacted through critical self-reflection coupled with action (Freire, 1970). Resistance is inherently political. Foucauldian resistance theory assumes that disabled people and their non-disabled political partners are simultaneously individuals and members of a collective. As such, experience and its influence on the construction of the disability identity are as important as the macro-social processes of disability community-building, disablement and the oppression of entire groups of people. The key is to understand and frame individual experience from a disability studies standpoint rather than from the singular disciplines of psychology or medicine" (Gabel & Peters, 2004, p. 594). This way of growing also becomes visible in the six years of primary school for Sofie. She is unfolding herself in all her complexity and multiplicity. She brings us and we bring her to many different roles, interests and potentialities in progress. One moment it works out better than the next: the fixed, categorizing structures can be questioned, but classification, assessment and labelling cannot be completely disregarded. Becoming-Sofie is always confronted with the limitations of her status as 'severely disabled child', 'child with cerebral palsy', 'child in need of extensive medical care', 'child with special educational needs' and similar categorizations. Resistance is organized at a rather ad hoc basis, forming contemporary coalitions, tentative alliances and strategic co-options of root-like or striated elements (Morss, 2000). Sofie and her parents resistance is not confrontational (Sotirin, 2005), they are working underground in a rhizomatic and connecting way. They do not bang on the table and transform our dominant discourses around education or disability. They are just moving in between the binaries, they engage themselves in 'contagious' micropolitical movements 'capable of crossing and

impregnating an entire social field' (Deleuze and Guattari, 1987, p. 276) and are fighting against limitations and exclusion. This is resistance through becomings (Albrecht-Crane, 2005).

Scott (1990) calls these movements hidden transcripts of resistance. The hidden resistance arises out of the private transcript but it never becomes public. It takes place under cover, beyond the view, and is the strategy that avoids direct or indirect conflict because there is no challenge for the public script. Scott explains that the dominant class can most easily tolerate a breach in application more than a challenge to the underlying ideology of the public transcript. Scott (1990, p. 203) explains: "Here the crucial distinction is between a practical failure to comply and a declared refusal to comply. The former does not necessarily breach the normative order of domination, the latter almost always does." With hidden resistance the public transcript is not changed. It remains intact as Sofie and her parents find another way without immediately challenging it. "The hidden transcript, the actions of the oppressed groups that take place 'offstage', is characterized by resentment and contradictions to what was performed in the public script. Although power relations are not so simple that we could say that everything that is said in the public script is false and everything that is said in the hidden script is true, the latter is built for a different audience and with different power constraints than the public script" (Lunat, 2009, p. 4). Nonetheless, even without a clear statement of ideological resistance, a single effective act of resistance has an effect. According to Scott (1990, p. 205): "A single act of successful public insubordination, however, pierces the smooth surface of apparent consent, which itself is a visible reminder of underlying power relations."

Resistance is "a type of cracking that is micrological, like the small imperceptible cracks in a dish" (Deleuze and Guattari, 1987, p. 198). The micrological cracks are the agent of becoming, they undermine the power exercised by dominant discourses through the way they govern what we see as the 'truth', our acting and doing. It is always the micropolitical that makes it or breaks it (Deleuze and Guattari, 2004). "With inspiration from Deleuze & Guattari, Rose refers to this [resistance] as 'minor engagements... (which) are cautious, modest, pragmatic, experimental, stuttering, tentative... (and) concerned with the here and now, not with

some fantasized future, with small concerns, petty details, the everyday and the not transcendental' (Rose, 1999, p. 280)." (Dahlberg & Moss, 2005, p. 14).

Becoming-child

Many children with a disability in inclusive education have a (long) personal history of persisting and surviving, sometimes going through several education and health systems. Children are talking about themselves, their abilities, their difficulties and daily lived experiences. They are blurring and breaching boundaries in a constant stream of playing with certain social expectations and they live in between the 'regular' and the 'special' world. "Becoming explodes the ideas about what we are and what we can be beyond the categories that seem to constrain us" (Sotirin, 2005, p. 99).

It is important to view and experience students as potentials –as virtual spaces that have the possibility for actualization. A subject according to Deleuze and Guattari is a continuous becoming not defined by static concepts and categorization such as disabled/able-bodied, male/female, gay/straight or even person/thing. Subjects, bodies, minds and rhizomes are connected, constantly produced, shifting and changing. Within these multiple, heterogeneous and rhizomatic processes of transformation of self and others, we are able to understand 'disability' as a new, unstable and uncertain flux of self. Gibson (2006, p. 191-193): "A fluid body, not a subject, but a conglomeration of energies. It is an excitation, a point of contact... an AND: a re-imagining of disability as a fluid category that we can/will all move in and out of."

Children themselves recognize that they are different but as they make clear, this difference only becomes relevant at certain times in particular contexts. Petra Kupperts (2009, p. 223) recognizes that fluidity in what she calls 'rhizomatic model of disability': "It allows the co-existence of 'not only different regimes of signs but also states of things of differing status' (Deleuze & Guattari, Plateaus 7) and that last part of the quote, things of differing status, resonates with my lived experience of disability as one that lives in a simultaneity of codes, devalued and valued at the same time. The rhizomatic model of disability produces an abundance of

meanings that do not juxtapose pain and pleasure or pride and shame, but allow for an imminent transformation, a coming into being of a state of life in this world, one that is constantly shifting and productive of new subject/individual positions. This rhizomatic model of disability is only useful when used. It cannot have truth status, for it is empty of specific meaning. It is a movement rather than a definition."

When teachers can tune in to this fluidity, they re-think their representations of children with special educational needs and teaching based on different levels. Learning levels have the implicit feature that there exist low and high levels. It is not a movement, but a fixed statement that we can test and measure. Becoming suggest a lot of different styles of learning that we cannot judge. We can only give opportunities and follow the flows children present us. You have to learn to see with 'new eyes': carefully observe what children can do, expect evolution (even little steps) in their learning and practice positive language to talk and write about this. Rinaldi (2006, p. 131) compares learning to a bowl of spaghetti: "Learning does not proceed in as linear way, determined and deterministic, by progressive and predictable stages, but rather is constructed through contemporaneous advances, standstills and retreats that take many directions." This is not easy, it needs a lot of practicing and goes together with many insecurities.

Becoming-teacher connects on this point with becoming-child. Teachers think critically about what they ask from their pupils. Teaching is not only a technical matter of didactics and control over a group, it is about an encounter. Teachers want to teach and at the same time they need to loosen up and be flexible. Teachers play an important role in accommodating to the learning style of the child. Sylvie, the teacher of Carlos in kindergarten says: "If I look at my moment of graduation and now, a lot has changed. You have to evolve and keep on learning as a teacher. A good teacher thinks about what children are supposed to learn. We expect a lot because it is our standard curriculum and we think that is normal. When I look at Carlos, I see one miracle after the other, each step he takes is a victory. Developing is not going from A to B, just like that. It makes me think more carefully about the activities I introduce to my children. Can everyone take part in what I present?" Sylvie would understand Michalko (2008, p. 413), who says: "Disability is not merely to

be educated about, thereby contributing to the solution of the trouble of disability. It is not merely a condition some of us have and to which we must adjust. Nor is disability something that needs to be deemphasized in favor of privileging the sameness of personhood. Disability Studies recommends that we, including educators, are parts that make up the whole of what we call disability. In this sense, disability is a teacher. It disrupts our conventional views of the 'normal' body, of what it means to educate and be educated, and of what it means to be human."

Becoming-child covers positive and negative experiences. We cannot 'protect' children from that, becoming is a very natural, fluent process that the child nor his/her environment can control. It covers feelings of belonging and involvement just as well as experiences of isolation and exclusion. "The active use of the term becoming allows the child (or whoever to which the competence is attributed) to be whatever it is, bilingual or non-speaking, happy or sad, socially skilled or uninterested" (Wenzer, 2004 in Ollson, 2009, p. 45).

Isarin (2005) talks about becoming-child in terms of the 'who' and the 'what' of the child. The 'what' defines objective or objectified differences between children in medical, psychiatric and professional terms and categories. The 'who' is the subjective singularity of the child. It is the person, regardless or just because of his/her disability. The 'what' "is coming together with everything that is not expected, not planned, not hoped and not wished" (Isarin, 2005a). It makes a clear difference between the child and his/her environment; a difference that is described in negative terms of deviance and behaviour. We know the 'what' as the label or the diagnosis that often describes people, seemingly objective, but burdened with a lot of negative connotations. The label(s) is (are) only part of the child. "Behind the dominant and burdened disability hides the 'who'. The 'who' is through and through relational; it can only be recognized and acknowledged in relation with the person" (Isarin, 2005b). It is the proper noun (the 'who') that sometimes threatens to disappear behind the generic name (the 'what'). We cannot explain the 'who', we can only experience it in connection.

Becoming-parent

"Becoming nomad means to desire the self as a process of transformation, to desire change, flows and shifts and to reinvent a multiplicity of selves" (Braidotti, 2003 in Roets, 2009, p. 693). Fathers/mothers experience this kind of transformation "which is incomprehensible, places the person on the fringes of a culture he or she was once part of, puts him or her in a position akin of that of the subaltern. A becoming can function as a source of creativity, a possibility of new beginning" (Nashef, 2010, p. 30). We could see this coming back in several stories. One mother mentions that in all the searching around the education of her son, she discovered many (new) talents in herself. She feels so much stronger now. She used to be quite timid and hardly dared to speak her mind, but through the years, due to the situation of her son, she became much more self-assured. These parents start 'travelling', go on a 'long journey' and take unexpected steps with their child and in their personal lives.

Becoming is strictly a matter of deterritorialization (Deleuze & Guattari, 1987). Parents move, in Deleuzian terms, the centre to the periphery and to the limits. Their confrontation with the otherness has imposed a becoming and challenges the pre-existing order of giving birth to 'healthy', 'normal' and 'fully active' children. They are confronted with life in-between, life at the 'borderland'. As Estrada and Mc Claren (1993, p. 28-29) suggest: "La Frontera (Borderland) is a place where cultures collide creatively such that the identities of those who 'cross over' are enriched and challenged. Identities that are not simply vehicles for the production of sameness (...), but identities that enable us to cross borders and experience different cultural locations." Devlieger (2010, p. 82) develops disability as an interstitial category, that "brings out the central characteristics of ambiguity, in that it situates itself between recognized cultural categories from which it proceeds to become dangerous, polluting, and challenging of the classification system".

Parents transform with the experiences they gain together with their child with a label, but also in interaction with their environment, the professionals and themselves. Isarin describes this transformation as "narrowing" AND "widening their view" (Isarin, 2005a). In the beginning their world falls apart, everything that is familiar disappears with the

daily care of their child. The life of the parent is reduced to the care and the worries around the child, not knowing how to feel towards this unexpected child and the confrontation with all the disability-experts. Slowly, parents refine their balance and can open up their view again: they can pick up their own lives again, but it is never like before, there is a child who needs their attention and advocacy that takes a central position.

According to Isarin (2005a), this transformation can also be described as “more vulnerable” AND “more strong”. Parents become vulnerable: their control is –in their feeling- blown away, a child with a disability brings from the beginning a lot of unpredictabilities and questions. They have to look for new connections and alliances while they are confronted with upsetting feelings that nobody can fully explain or understand. The vulnerability stays and has very strong moments like in transition periods or when the child’s health is unstable. At the same time becoming-parent opens up a strength that not many parents knew they could develop. They show more patience, assertiveness, are less touched by authorities and social codes. They gather situated knowledge around their child and the upbringing of the child. They have to “lodge [them]self on a stratum, experiment with the opportunities it offers, find an advantageous place on it, find potential movements of deterritorialization, possible lines of flight, experience them, (...) experiment, living-in-itself, connect, conjugate and continue” (Deleuze and Guattari, 1987, p. 161).

Becoming and support

Be able to say what support you need or find necessary and handle support is part of becoming for children (and adults) with a disability. Often children tell us about the big anxiety of their parents, the overprotecting teachers, the support workers that hinder contacts with peers and teachers. Support cannot slow down or stratify becoming-child. “An ethic of care would justify providing care when care is required and eliminating not all dependency, but just those dependencies that undermine or interfere with the freedom to exercise whatever capacities one has or can develop. A person who cares for another with the attention required of good caring, provides care and assistance when

it is needed and not when it interferes with the other's justifiable need and desire to be exercising her own agency. Both bearing the burden of unmet dependency needs, and being falsely seen to be dependent in ways that one is not, serve to exclude disabled people from participation and the possibilities of flourishing. Furthermore, people with disabilities are often thought to be disqualified from caring for dependents when in fact they can and do take on these responsibilities" (Kittay, 2005, p. 458).

Disabled children spend a large amount of their time in the company of adults and in social spaces where adults are actively present. Most of the children think very positively about support that is related to positive consequences: they do more work and it is easier to participate in the activities just like peers. Children are also explicit about doing things on their own. They want to do things independently as much as possible. As a professional we need to be aware of our role and the influence of the person we support. This is an important branch of becoming-professional. Connecting to a child with a disability, his/her story and his/her parents teaches the professionals to constantly monitor and change our position; we have to be able to leave our own goals and tasks. We have to step into the 'shoes' of the person they are supporting. We are not only professionals but also human beings AND women/men AND mothers/fathers AND... We have to admit that we do not know sometimes. Professionals can only give support if we are willing to leave our known expert-territory and go into dialogue with pupils and parents. "In hosting others [children with a disability and their families] we change, hybridize our discourses and identities, and let others teach us, from the beginning, how we are different and multiple in ourselves" (Gregoriou, 2001, p. 146).

Becoming-teacher or becoming-support worker involves a constant critical and reflexive attitude towards our work. "It is questioning and induces stuttering, disrupting discourses and publishing accepted meanings, denaturalising the taken-for-granted, opening up issues to confrontation and contestation. It makes us aware that our constructions are constructions which are produced in particular contexts and shaped by particular discourses" (Dahlberg & Moss, 2005, p. 138).

Instead of using preset models and positions, children, parents, teachers and support workers as well as the content and form of learning processes take on the features of moving in a relational and transforming field. Becoming needs becoming to the community. "Everything is involved in such a field, not only human subjects, but also the content of knowledge of different subjects as we know it, as well as the entire milieu. These are all in relation, as multiple identities encountering each other: it is the relation itself that is in movement, always becoming" (Olsson, 2009)

7.2. Desire

A child with a disability is in constant becoming, a continuing journey which has no beginning and no end, it is always in the middle, always between things. Deleuze and Guattari do not think in terms of a stable and fixed identity but "a nomad, an assemblage that crosses borders and categorizations" (Styhre, 2001, p. 8). Desire is the driving force behind becoming. "Starting from the forms one has, the subject one is, the organs one has, or the functions one fulfills, becoming is to extract particles between which one establishes the relations of movement and rest, speed and slowness, that are *closest* to what one is becoming and through which one becomes. This is the sense in which becoming is the process of desire" (Deleuze & Guattari, 1987, p. 300 - 301).

Desire allows ongoing movements, flows and transformations. Diedrich (2005, p. 238-239) describes desire as "productive forces, creating other subjectifications, other knowledges and other futures." Desire works as: "An opening up to difference, it is the capacity to *affect and be affected* that offers a potential for social improvement and progress and is thus affirmative since it makes us continually reach beyond ourselves and society and so constitutes the human condition as self-overcoming. For Deleuze, desire makes us Human, yet always more than human, we are able to be more than how society would represent and constrain us" (O'Shea, 2002, p. 931).

Desire pushes us and leads us to new and positive horizons. We have to be prepared to work with potentialities: "Desire is an unconscious process of production: it concerns a kind of learning that it is not possible to tame, predict, supervise, control and evaluate according to already existing standards" (Olsson, 2009, p. 185). We discover always new connections and possibilities. We construct and reconstruct ourselves and our world of assemblages over and over. We do not have to look for these processes very hard, they just happen. "Productive desire is a power, a passion that moves one towards something new, the other. According to Deleuze & Guattari desire does not lack anything, it does not lack its object. It is, rather, the subject that is missing in desire or desire that lacks a fixed subject; there is no fixed subject unless there is repression" (Gibson, 2006, p. 189).

The desire provides us with situations of deterritorialization. Children with a disability are looking for moments to escape and find lines of flight. They resist stratifications and dichotomies. Tamboukou (2003, p. 221) believes that: "Education has always been constituted as a significant locus of resistance, a smooth space for forces of deterritorialization to be released." It is very hard to describe those moments, we can feel the effect: these are raving moments, moments that give us goose bumps. Parents, teachers and children throughout this thesis give several examples of this going beyond all expectations. I describe one situation where I felt it myself: "The teacher calls two children at the blackboard. The other children have to follow what they make of the mathematics exercises. The teacher comes to put things ready for art class. Sofie looks at him and makes noise. The teacher looks at her and asks: "What is going on, Sofie?" She smiles. He takes a string of paper and comes to her. He is waving with it. She finds this amusing and laughs while she stretches her body. He is making a lot of moves and is over-acting while he asks: "What is so funny, Sofie?" She keeps on making noise and is smiling with all her teeth visible. He puts the green, paper string around her neck: "Do you want to wear my necklace?" He turns himself to the other children that are watching: "Look at Sofie. Isn't she pretty?" Children watch and you can hear admiring: "Oh!" and "Ah!" Some are laughing. The teacher wants to return to mathematics: "I am going to remove the chain, Sofie." Sofie keeps her head against her headrest, very firmly. The teacher cannot remove the string of paper. He tries again: "Come, Sofie, I am

going to take my paper back." She slowly bows her head. The moment the teacher takes the string, she moves her head very quickly against the headrest. This repeats itself two times. Sofie finds it very amusing and the children are laughing and watching what the teacher will do. He says: "Uncontrolled? You must be kidding!" The teacher leaves her alone and goes back to the blackboard. He puts two other children at work. Then he returns to Sofie: "Seriously now, I am going to remove the string." Sofie bows her head and the teacher can take the string without any problem." (Observation 4th grade, 22.01.2003).

When we take desire seriously, it has consequences for the way we look, think, talk and represent children with a disability. It comes very close to Rinaldi (2006, p. 92) who uses the term 'competent child', the child "who has the ability to learn, love, be moved and live, the child who has a wealth of potentials, the powerful child in relation to what (s)he is and can be right from birth. (...) Competent because he/she has a body, a body that knows how to speak and listen, that gives him/her identity and with which he/she identifies things. A body equipped with senses that can perceive the surrounding environment. A body that risks being increasingly estranged from cognitive processes if its cognitive potential is not recognized and enhanced. (...) The body as a site of knowledge, pleasure, affection and desires. (...) A body that we must not be afraid of, but take care and respect. A body that is a mean of gaining knowledge. Learning by means of the body has been a common way of humankind and specifically of young humans." When we look at a child with a disability as a 'competent child', it becomes a fascinating child, a child that intrigues, that we want to know.

Desire instead of need

Children with a disability spend a lot of time talking about things which they think they are good at and able to do. This is not always related to their intellectual abilities. Their interests and talents can become points of contact in their learning process and can help to make choices, add content to subjects at school, give direction to their field of study and leisure time. If desire is productive then (disabled) students are always considered productive. The nomadic learner rejects the static/fixing assessment of impairment labels offered by 'statementing' and

'diagnosis' (Goodley, 2007). Eva Kittay (2001, p. 260) recognizes the importance of desire in the capacities and difficulties of her daughter, Sasha: "Her limitations describe the face she shows to those who don't know her, but they also convey the ways she cannot make her own way in the world. Knowing her capabilities, one gets a glimpse into the richness of her life and the remarkable quality of her being. (...) Only by considering her in the fullness of her joy and capacities can we view her impairments in the light of her life, her interests, her happiness - and not as projections of her 'able' parents of an able-biased society." Allan (1999, p. 116) assigns teachers a significant role in this struggle between desires and needs: "Teachers might help pupils to explore their sense of self - expressed as desires rather than needs - and to analyse the constraining and enabling factors, but should avoid passing judgments on them." This contains a plea for a more rhizomatic making sense of becoming-child that helps teachers and parents search how they can best support the child's learning and growth. "In forming rhizomes the impaired subject expresses the drive and desire to be, to become and to act. The dominant disability discourse of impairment as functional deficit, personal tragedy and lack, rooted in arborescent, hierarchical (but social) networks, undergoes a critical deconstruction within dynamic and reflexive networks of social engagement and activity" (Goodley & Roets, 2008, p. 243).

At this moment, the desires, plans, dreams and capacities of children with a disability are most of the time irrelevant for the care, revalidation, rehabilitation and treatment they receive. It is okay for the introduction, but no substantial part of the work together. "By proposing that desire is production of real, lack or need can be positioned not as a cause but rather as an effect. Within the logic of desire as lack, mad people and children become 'needy' since institutions never capture their desires as production of real, but reduce them, tame them and adapt them as signs of need and lack" (Olsson, 2009, p. 145).

At the beginning of her life, Sofie acquired the labels of 'cerebral palsy', 'complex and multiple impairments' and 'deep mental retardation'. These were the justifications for the school/care system to place her into a system of segregation. It was 'clear' that Sofie needed special education with considerable medical attention, a small group, a lot of rest and

individual working, surrounded by many professionals. "When the time came for my daughter to go to school, we followed the path that we thought we should follow. It was very difficult to subject her to an intelligence test. A multi-disciplinary team referred her to a special school 'type 2', for 'children with moderate to severe intellectual disabilities'. They gave us an overriding motive: our daughter had multiple medical problems and the school had a well-equipped medical department" (Rita, mother, 18.01.2003). Her orientation in education was based only on her needs and deficits, not on her own capacities and desires and those of her family. If we allow these defects to determine her opportunities to participate, we are constantly legitimizing reasons for segregation. After two years and a few struggles between her parents and a number of professionals, she was passed to type 4 education (for children with motor impairments). "The school that agreed to try it, warned us from the start: it will probably not be for longer than two years. 'Your daughter doesn't really fit in our target group', 'she shows no interest', 'the gap between her and the other children is too big'... We saw her make huge progress and she really tried her best in those two years to catch up, but it wasn't enough for the school. Our daughter did not reach the standard for primary schooling in special education" (Rita, mother, 18.01.2003). Sofie experienced (and experiences) many times, over and over again, a dominance of binary thinking in terms of normal/abnormal, disabled/non-disabled, regular/special, dependent/independent and so on. She is not achieving all of the (developmental) goals set for children of her age. Sofie does not meet the institutionalized norms of school/society in special nor in regular education. When we look at her as 'a competent girl', this is not necessary. Sofie cannot 'fail'. We are looking to catch and facilitate her abilities and capacities. "Through their understandings of 'attention', Weil and Murdoch suggests that by listening to the others we might move from what Foucault called a 'disciplinary gaze' to what might be described as an 'attentive gaze'. Where a disciplinary gaze is directed to what someone is judged to be, an attentive gaze looks at what is not and perhaps cannot be known about them; who they are in and to themselves. The former seeks to control, the latter to understand. (...) Only an attentive gaze can see past fog [of labeling], for this gaze is always directed towards, and always seek to reveal, originality and mystery" (Veck, 2009, p. 147).

Focus on connections

Desire is productive. "It is always assembled and it is clearly connected also to language and bodies that go through a rhythmic art of re-and deterritorialization, breaking out and settling into habits as territories. (...) Assemblages of desire are multiple within individuals as well as within society. We are all assembled, society is assembled, and the distinction individual/society has to give way for assemblages where the relation between individual/society finds itself in continuous movement and thereby open for intense and unpredictable experimentation" (Ollson, 2009, p. 55). According to Hickey Moody (2007, p. 98) we can see an 'assemblage' as "a contextual arrangement in which heterogeneous times, spaces, bodies and modes of operation are connected". We act and live in assemblages, starting out from unconscious desires that we cannot control, we construct assemblages through and with other people.

These flows of desire do not think in terms of 'minimal goals' and 'competencies' every individual has to achieve. "The desire to connect, make things happen, and extend one's own capacities and powers to affect and be affected – the productive desire that constitutes active participation in the creative diverging of life" (Lorraine, 2008, p. 62). Deleuze and Guattari present us with the provocative possibility that desire does not have to be about what a personal self wants, but could be about connecting with the world, making things happen and experiencing what happens in ways that defy subject/object and self/other dichotomies. Diedrich (2005, p. 242-243) adds: "Desire produces connections and create belonging. (...) belonging in constant movement."

The reciprocity between the individual and the surrounding environment is the focus of attention for teachers. They are part of the assemblages and use these connections to support the desire. When the teacher works with a child, he/she does not see the child, but the relationship and the quality and the limitations of the relationship. "A pedagogy of desire inspired by Deleuze-Guattarian thought provides different strategies for working through power relations among teachers and students. Instead of trying to situate them in a dialectic context, a pedagogy of desire aims to explore the various, social, material and political manifestations of one's

existence and its connections to others" (Zembylas, 2007, p. 340). This idea of connections of desire, not only between the child and the teacher, but also between children, regardless their capacities, opens up a source of natural solidarity, and enormous amount of possibilities to learn in connection. It is about 'us' (Bogdan & Taylor, 1989). Sanne (teacher of Charlie in 4th grade) explains: "The value of inclusive education lies for me in the feeling of WE in this group. There is a lot of willingness to work together and children are very open to learn from each other. To learn to support and take care of each other is something they take with them for the rest of their lives." Desire has "to do with cultivating and facilitating productive encounters, which sustain processes of self-transformation or self-fashioning in the direction of affirming positivity" (Braidotti, 2006, p. 3).

Question independence and autonomy

We are educating and preparing children in all kinds of different trajectories, in regular and special education, in kindergarten until university for autonomous citizenship. We have to be able to take care of ourselves, discover and develop our talents and prove our capacities in the terms of productivity and individual outcomes. "It calls for an active citizen: a citizen able to speak up for his/her own interest, a responsible citizen who has no rights without duties, cherishing the values of 'free choice' and taking responsibility over his/her life as a personal entrepreneur and therefore actively participating in the democratic fora that are made available to him" (Masschelein & Quaghebeur, 2005 in Vandenbroeck, Roets, & Snoeks, 2009, p. 212). It all depends on our individual engagement and work. When we think about it from the perspective of children and adults with a disability, they can often not meet 'The Standards'. Kittay (2001, p. 560) writes about her daughter with serious impairments: "An exclusive focus on her limitations would set her outside liberal definitions of personhood and citizenship that are fixated on intellect, independence and productivity. These values throw into question her entitlement to the resources she needs for her full development and flourishing." It is very clear: "Individualism and autonomy limit desire by promoting independence and self-mastery as ends in themselves and rewarding their successes. (...) The goal of independence limits desire and the appreciation of connectivity. It

reinforces disability as limitation rather than possibility and thus may contribute to legitimizing the repressive systems that exclude disabled people. It assumes that inclusion in these systems is worth pursuing. Perhaps, it is not. Perhaps, there are possibilities in experimenting with various forms of dependency, giving and receiving, expecting nothing and everything" (Gibson, 2006, p. 190).

A focus on desire instead of needs and limitations provides a serious task to education in our society. "An ethic of care regards dependence as a central feature of human life and human relationships and interdependency rather than independence as a goal of human development" (Kittay et al, 2005, p. 453). Rinaldi translates it to a pedagogical relation: "Children's learning is situated in a socio-cultural context and takes place in interrelationships, requiring the construction of an environment that allows for maximum movement, interdependence and interaction" (Rinaldi, 2006, p. 6). It should be very clear that the interaction between child and environment is very important. Children "do not perform their agency, alternating sameness and difference and performing hybrid, nomadic identities in a vacuum. It is the welcoming ability of the staff [teachers and support workers] that creates the context in which this agency or this relational citizenship takes form" (Vandenbroeck, Roets, & Snoeks, 2009, p. 213). This works also the other way around.

Working with affects in education

Affect is what makes us going, it is about our 'inter-esse' in the world and it is unconsciously available through desire. Deleuze sees affects as powers of desire that flow continuously and make connections inside and between machines (Tamboukou, 2003; Zembylas, 2006). It is "intensities of movement, rhythm, gesture and energy" (Tamboukou, 2003, p. 216), which leave space to connect through their rhizomatic openness. We could see the class as a space where the values of affects are expressed. Education can make a difference and provide many opportunities for transformations via deterritorialization and line of flight (Tamboukou, 2003, p. 209). "How do we experience our affective privileges as well as our lack of affective resources? (...) To call for pedagogies that do not privilege rationality, and to decide when and how affects can and should

be articulated is truly problematic and challenging... But if we follow these lines of flight, away from stagnant habits and towards collaborative affective inquiry, we open affective territories that promise passionate educational exploration not yet colonized in the economies of mind." (Boler, 1997, p. 268-269)

To allow and acknowledge affect can offer opportunities to inclusive education. The goals of the standard curriculum are not the untouchable golden 'cows' of education. We have to realize that the goals demand a lot from children and are firstly focused on individual development and independence. Inclusive education asks for belonging and takes away the emphasis on individual outcomes and competencies. This does not imply that we have to break with a knowledge-based curriculum (Allan, 2008), this would never be attainable nor desirable. We need to create space for something else, that is not possible to define clearly, that promotes re-thinking and re-seeing, where affect and experience are granted an equivalent importance. Affect is part of 'becoming', it is thriving force in the relational field. Affect is perhaps the 'intuitive' idea which drives on us, in a light-footed teamwork with desire.

There are many occasions where Sofie affects and is affected through primary school. It happens in a very detailed way between Sofie and her environment. "Affect is thus understood both as a process and a product: a process in which one body acts upon another, and a product in the sense of a body's capacity to affect and be affected. The intense capacities of a body to affect and be affected are an essential component of experience. The production of a body involves an encounter with other bodies; the powerful intensity of this encounter marks the body's capacity to act" (Zembylas, 2006, p. 309). These moments impress and influence the relationships, but that is not all. This thinking in terms of 'affect' puts people constantly on the move. There is a gigantic source of learning opportunities offered unconsciously within the classroom. The power of 'affect' works incredibly bounding in two directions, it can be positive and negative and we can often observe only the effect. "Differences among bodies are materialized as relationships and affective encounters – they are not inherent to a particular body" (Zembylas, 2006, p. 317).

7.3. Ethical encounter

“Orthopedagogics concerns a meeting or encounter between persons, a search for adapted methods and ethical positioning” (Broekaert, 2004, p. 206). The encounter is our most important tool to engage with other people in action and reflection. Following Braidotti (2005, p. 13), I want to stress the need for a positive ethics: “It is an ethics based on the necessity of meeting the challenges of the contemporary transformations with creativity and courage. The challenge is how to put *active* back into activism. As far as this position entails accountability for one’s historical situation, it expresses not only a sense of social responsibility but also an affect”.

At the same time, this encounter makes our reality very ambiguous and uncertain. There is no black and white, only varying shades of grey. What we know, is that we don’t know (much). We can discuss our actions and negotiate our positions towards one another, ‘expertise’ is not fixed and flows in the encounter between subjects involved. “Reframing inclusion as an ethical project takes us into a politics of desire in which ‘the only possible way to undertake this process is to actually be attracted to change, to want it, the way one wants a lover – in the flesh’ (Braidotti, 1997, p. 70) (...) Since we can never fully satisfy desire, the ethical project of inclusion will inevitably remain a work in progress” (Allan, 2005, p. 293).

For making sense of our ethical encounter I turn to Levinas who describes this relation as an absolute and infinite responsibility for the Other. Ethics is born in the relation of proximity to the Other: “The term ‘ethics’ always signifies for me the fact of the encounter, of the relationship of an I to the Other... Transcendence and proximity. It is before the Other and the face of the Other that one can have the pure experience of the other, in as much as one is aware that one is responsible for the other, that the existence of the other is more important than one’s own” (Eg  a-Kuehne, 2008, p. 32). What do we do and how are we able to respond, depends on the Other. An (ortho)pedagogue is a companion and support-worker, going on a journey together, without knowing any

final destination. This is very different from the goal oriented education that dominate our teaching approaches. It takes time to really become aware of the complexity of the Other, his/her environment and the questions that arise. We are committed to the Other, it is much more than a 'technical' job where we think linear and solution-minded. Strahn (2007, p. 419) is clear: "To be taught in the encounter with the Other whom I desire is a perpetual movement of SEARCH, never satisfied and beyond the order of labour and economic exchange".

Responsibility

"As we interpret Levinas, ethics of care can be seen as learning from the Other. If a teacher is caring for her students it means a responsibility for the Other. This also means openness to the Other's abilities and a will to be part of the relationship and also be a learner. It is not only the student who is learning something in a learning encounter. Levinas (1969, 51): It is therefore to receive from the Other beyond the capacity of the I... this also means to be taught. The relation with the Other, or conversation is... an ethical relation... this conversation is teaching. Teaching is not reducible to maieutics, it comes from the exterior and brings me more than I contain" (Bergmark & Alvery, 2006, p. 12).

The emphasis is on obligation to the Other without expectation of a profitable return. It is through the acknowledgement of and openness towards the Other that I am in constant engagement with myself. There are no restrictions on the reciprocity, there is an unconditional responsibility: "I have to respond to and for the Other without occupying myself with the Other's responsibility in my regard" (Levinas, 1987, p. 137).

Responsibility is a matter of giving without calculation, of making space for the Other in our own world and welcome the Other in our house. The Other is asking us to respond and is counting on us. "Responsibility is about surrender and openness to the other, about saying 'yes' to the otherness of the other, and about suffering through anxious situations not of our own making, but to which we are nonetheless called to respond" (Cinnery 2003, p. 7). The totality can only be broken if we respond to the appeal of the Other in a concrete and material way when

we show love, generosity and affection. "In no way can responsibility be instilled or inculcated in a direct fashion and thus it cannot be systemized into any curricula or teacher manual" (Todd, 2008, p. 175).

Openness requires flexibility. A teacher or support worker cannot deliver standard packages of service. What we do is respond to the Other, a result of listening to and negotiating about what people want you to do and the support they require. The appeal of the Other is so strong that we cannot do other than follow and serve. It demands a response that cannot be prepared beforehand, we have to surrender. Isarin (2005a): "I am convinced that professionals only can [surrender] if they look at their own lives. The moment professionals acknowledge their own vulnerability and ambiguous feelings in their own life, they can really connect to parents."

Open up and respond is about curiosity, communication and being able to follow. It has no point to fight. The only thing we reach, is that people feel not understood and cannot listen any more. We follow their way of thinking, we listen to their story, and we show real commitment to go with their ideas and way of looking at their child. We have to show interest, real interest and ask questions. Only at the moment parents feel really heard and respected, they can come more open for different opinions or exchange of opinions. As a parent they often have the idea they have to defend themselves and their child.

This degree of openness also brings risk: "It is the exposure to the Other in which a risk is taken, a risk to suffer without reason, for nothing. (...) In order to enter into an ethical relation with the student, the risk embedded in the saying is an inevitable one. It is an uncertainty and vulnerability of uncovering oneself for the student. The risk (...) makes the welcoming of the other possible" (Safström, 2003, p. 25-26). In being a *compagnon-de-route* for children and parents, we have to give up your 'safe' position as the professional. We have to be prepared to go deep and far and get our hands dirty. We share moments when they feel pride when success has been achieved. We also cry when people are disappointed, damaged or deprived of their rights. We cannot shut out the pain or frustration nor the intense joy people face.

We have to dare to question ourselves. If we go through very difficult moments, we cannot put everything that goes wrong on the child's shoulders. Often it is very important to be able to admit mistakes, re-think situations and look for (new) ways to handle it. It is recognizing the complexity of the child and his/her environment, be open about what we are doing, formulate (new) hypotheses, search for (different) ways to make it work and reflect critically our own actions, over and over again. If we are honest and talk together with children and parents about our work, then we can really work together. A trustful relationship between the Other and I can grow. "Such an ethics, informed by Levinas and not in itself a theory, but rather a reorientation to human subjectivity has as its core an absolute responsibility to the Other because of one's own inadequacy in the face of the demand of the Other" (Critchley, 2007 as cited in Allan, 2009, p. 7).

"Responsibility is for the Other, with the Other. I am, as Levinas says, the hostage of the other. Responsibility is not my property, I cannot re-appropriate it, and that is the place of justice: the relation to the other" (Derrida, 1997, p. 27). It makes us very humble in encounter with the Other. Safström (2003, p. 25) poses the question 'Have I the right to teach [support]?': "This opens up the possibility for teaching otherwise, understood as a process in which an Ego is sobering up from its being for itself and awakens to humanity, as a being for the other. It acknowledges a radical and necessary uncertainty as a condition for teaching. It is continuously answered within the teaching that actually takes place, within the dialogue where response to the other becomes possible."

Uncertainties are running like continuous threads through this thesis. "Doubt, uncertainty and feelings of crisis are seen as resources and qualities to value and offer, conditions for openness and listening, as requirements for creating new thinking and perspectives" (Rinaldi, 2006, p. 18). We cannot predict what is going to happen in every situation, we cannot predetermine outcomes in every learning process. It is necessary to let go, but be alert and awake. Teachers are having doubts about what they can offer to children with a disability in their classroom. They feel very insecure. They ask questions like: Will I be able to respond to what the child asks from me? Can I teach him/her something? Are there enough or too much cognitive and relational challenges for this child? Do

I have sight on what the child learns at this moment? Teachers show that they feel responsible for the children in their classroom, also for the child with a disability. Parents are confronted with existential questions around their parenthood and the choices they make for their child with a disability. As a support worker and researcher I also encounter(ed) many uncertainties. These questions are part of work, of life. Sometimes we feel very scared, the fear can even paralyze, but the only thing we can do is just work and go on, one step at a time. Wyatt and Gale (2008, p. 363-364) understand us with the help of Deleuze: "Let's see what happens, let's see where it goes. The nomadic nature of our inquiries (...) seems to be like this. It seems that our lines of flight trace new shoots and pathways in the rhizome; I am always aware that we or I might be going off in another direction. What feels good about this is the feeling of trust that I have in doing this. I have a feeling – no, it is a knowing – that it will all come together. I have a sense of what we are doing and it convinces me of its worth, it encourages and motivates me to do more. This coming together is the becoming that Deleuze talks about, the folding and the unfolding."

The Other and I

The Other is crucial, the only way to be able to think and talk about me. The relation with the Other is an ethical relationship, where I am no longer in control. Safström (1999, p. 227) writes: "The Other gives the subject meaning. The meaningful subject, the self, becomes a consequence of the relationship to the Other – a relation which does not strive for the coinciding with oneself (Levinas, 1994, p. 118). Otherness becomes constituting for the subject's being." The ethical relationship is modulated through the way in which I "receive from the Other and am taught by the Other" (Todd, 2008, p. 171). Safström (2003, p. 22) describes this proximity between the Other and I as a social relationship: "The teacher's being for the Other is not to be understood as a negation of essence "but a desinterestedness, an otherwise than being which turns into a 'for the other', burning for the other, consuming the bases of any position for oneself as an Ego" (Levinas, 1994, p. 50)."

I have to take responsibility for the Other and this relation is one of welcoming the Other as stranger. "Our actions are not based, on

reasoning and principles, but it is 'feeling with, and for, the Other that motivates us in natural caring' (Noddings, 2002, p. 4). Care is a reciprocal act, and Noddings (1984, 2002) talks about a relationship between the cared-for and the one-caring and that people can learn to both give and receive care. In this relationship between one-caring and the cared-for, the carer has to discover the others need and respond to them in an appropriate way. The act of caring is only received when the Other accepts the act." (Bergkamp and Alerby, 2006, p. 4). The ethics of care is relational and situated (Noddings, 1984).

Dahlberg & Moss (2005, p. 70) point very clearly the paradox in the relationship between the Other and I: "It is a relation characterized by uncertainty, dissensus, dissymmetry, ambiguities, interruptions, even, as Derrida has said in relation to Levinas's ethics, impossibilities. But at the same time is also the chance of human togetherness, which is the condition for love and friendship. (...) Being-together presupposes infinite separation and dissociation. It's being utopian does not prevent it from investing our everyday actions of generosity or goodwill towards the other: even the smallest and most commonplace gestures... bear witness to the ethical. (Levinas & Kearney, 1986, p. 32)."

From the perspective of the parents, Isarin (2005a) outlines very nicely this double dependence in the face of the Other (in this case the professional: teacher, educator, supporter ...). "It means desire and curse support, help and compassion of another. It does depend on experts who can create and solve problems. Life with a child with a disability is living with contradictions: contradictions in yourself, in the child and in the environment." There is a difference in knowledge and experience between parents and professionals. First ones live their lives, and second ones do their work; both can do it passionately. It is important to be aware of moments of asymmetry in power AND moments of unconditional hospitality, no matter what. The difference in knowledge and experience can be meaningful but it doesn't need to be hierarchical.

Grasping: make the Other into the Same

Through grasping, the stranger is made familiar and intimate and the Same, and the unknown is turned into something which free thought can

grasp and have at its disposal (Kemp, 1992). This is an Other whom I try to totalise, that is “seek to understand through a framework of thought I impose on the Other” (Strhan, 2007, p. 414). “Difference is supposed to vanish, to be dealt with and to be exceeded in favour of a harmonisation of opinions and stands” (Safström, 1999, p. 224).

The Other always goes beyond my understanding: “The Other is infinity, and we can conceptualise infinity but we can never comprehend infinity.” (Taylor, 1987, p. 196) Rather than grasping the Other, Levinas requires respect for the Other. This calls for respecting the Other as absolute alterity: “The otherness of the student can be characterized as uniqueness, something that transcends my categorization” (Eppert, 2008, p. 79). It challenges dominant discourses, structural domination and oppression and opens up for new possibilities and potentialities. Following Safström (1999, p. 225): “Politics which is not striving for unification and the resolution of difference opens itself to those who are excluded, to silenced voices and to a politics of resistance.”

According to Devlieger, Rusch, & Pfeiffer (2003, p. 12), disability is about same AND different. “To understand that persons with disabilities are human and rightfully belong to the human category, but also deserve a degree of difference that connects them with the outer world, requires a flexibility of thought and method of inquiry that challenges much of what we are currently involved in.” Complexity does not come without ambiguity or struggle.

We see several teachers struggle with making the same and respecting the otherness. Teachers turn to the Other by inviting yes, yes, yes, and are trying hard to listen to the child from its own perspective not to make the child into the same. Chantal (teacher of Sofie, 3th grade) says: “I have had a busy, busy school year. I could enjoy with my class many very nice experiences. A very special ‘thank you’ to Sofie. She has taught me to see certain things, learn to approach from a different point of view: her position. I am her very grateful for this and feel enriched by this challenge.” Edgoose (2008, p. 103) sees the classroom as an ethical practice where “teachers and pupils are connected to each other. They bring their experiences and expectations when they meet in the school.

Their worlds overlap and there is potential for a meeting between the two”.

7.4. Pedagogy of listening

Co-construction

Children’s learning is situated in a socio-cultural context that takes place in interrelationships, requiring the construction of an environment that allows for maximum movement, interdependence and interaction (Rinaldi, 2006, p. 6). To be free, is to be bound (Cinnery, 2003). Children grow up with the idea that the other is necessary for their own identity and existence (Rinaldi, 2006, p. 116-117). Every subject is considered as a construction, “both self-constructed and socially constructed within a context and a culture” (Rinaldi, 2006, p. 138). Rinaldi prefers not to speak about a ‘person’ or an ‘individual’ because the relational and reflective aspects that matter in that construction are put aside. When children with a disability talk about ‘who’ they are, they talk about what they share with peers to explain their own interests. They show in lots of different ways that they can and want to belong. The children are looking for points of contact, want to contribute and be a valued member of the class and school context. When Nathalie signs her letters with her name and her class, she shows to be proud of being part *of* that group. It is part of who she is. The feeling of connectedness is very important in going to school. Most of the time children with a disability talk about field trips, school treats, what happens at the playground... In their support we also see the importance of creating bridges and supporting connections.

Rinaldi invests in a pedagogical relation “where knowledge is seen as constituted in a context through a process of meaning making in continuous encounters with others and the world, the child and the teacher are understood as co-constructors of knowledge and culture”(Rinaldi, 2006, p. 6). Teachers talk a lot about what they learn from children and how a positive and friendly relation with the children is essential in order to learn. Learning is seen in a very broad sense: it is not only about content, but also about learning to live together. Learning

happens in multidirectional ways: children learn from children, a teacher learns from the children, a support worker learns from teacher... Luc (teacher in 3th grade) says: "I think that all children in class can teach something to the teacher. I take with me from Tina her unique way of communication. Because I can communicate with her, I am convinced that everyone is able to communicate."

The class environment and atmosphere is very crucial in welcoming children and invite them to learn. A classroom is a web of connections that come and go, that change over time and in intensity. Creativity is an important tool to face all these challenges. Bert, the teacher of Arno and Ida in Kindergarten brings it into practice: "I was telling a story and Arno had to go to the toilet urgently. I had to stop working with the group and go out with him. I knew it was not just in and out for a second. I began to sing while I was putting Arno on the toilet. In that way I was close to other children. They heard me and I heard them."

Listening

When the classroom is a public space full of encounter, Rinaldi (2006, p. 70) describes listening as a social and relational process in which the expectations and behaviors of teachers towards children are orientated and responsive, rather than pre-determined and prescriptive. "Listening as sensitivity to the patterns that connect, to that which connects us to others; abandoning ourselves to the conviction that our understanding and our own being are but small parts of a broader, integrated knowledge that holds the universe together" (Rinaldi, 2006, p. 65).

Listening is not only hearing, but implies being sensible with all our senses. It is about sight, smell, touch, taste, orientation. We make use of our entire body, which creates the openness to 100 (maybe 1000) languages (Malaguzzi, 1993 in Dahlberg & Moss, 2006, p. 7) to express ourselves. This attitude and activity is guided by desire, uncertainty, interests and leads to questions instead of answers.

"Behind the act of listening there is often a curiosity, a desire, a doubt, an interest, there is always an emotion. Listening is emotion; it is generated by emotions and stimulates emotions. The emotions of others influence

us by means of processes that are strong, direct, not mediated, and intrinsic to the interactions between communicating subjects. Listening as welcoming (...), recognizing the value of the other's point of view and interpretation" (Rinaldi, 2006, p. 65).

Throughout the stories in this thesis, listening is a very important 'instrument' in the 'toolbox' of a pedagogue. Children, parents and teachers are looking for commitment; the only way to cross the bridge is feeling genuine interest. It is crucial to give people the feeling that they are not alone, to listen to their story and spend time with them. We analyse and interpret lived experiences from an open, curious and questioning stance. This orientation is in contrast to professionals perceiving themselves to be the 'knowers' in regards to children's learning, aspirations and participation. Listening is not a technical competence, it hangs closely together with building up trust and being able to show vulnerability towards the Other. I also follow Veck (2007, p. 2): "When learners are not listened to, they are denied the opportunities to contribute, to enrich and to challenge the culture, organization and character of the educational institutions and are, as a consequence, excluded within these institutions: they are in but not of them."

Difference

Acknowledging difference is an important way of listening (Rinaldi, 2006). Rinaldi asks for intersubjective spaces where difference can unfold and be understood instead of rejected. The Other is expected to conform to a majoritarian set of universal ethics, rules, norms, values, codes and discourses while the dominant group continues to benefit from society operating according to their ways of being and thinking. There are standardized expectations towards the development of children that are being tested on statistical models (like we have many examples in developmental psychology). Professionals feel very safe and familiar in using instruments that label learners in terms of what has been deemed deficient with them. The support children get is based on these 'objective' procedures. You cannot escape. "The child becomes content – not understood as child- but expressed through the significance of special educational need, the disabled. These generic categories lie on the

stratum (outside the child) but through faciality and inscription, the content is written on the body of the child" (Bayliss, 2009, p. 288).

In pedagogy of listening we move away from the totalitarianism of the Same (Dahlberg & Moss, 2006, p. 14). Rather than pathologizing difference, 'pedagogy of listening' acknowledges and invites differences, diversity, ambiguity, uncertainty and engagement with the Other in the pursuit of an inclusive and democratic society. "According to Terzi, difference within a capability perspective is neither deviance from a normal standard, as in the medical model, nor is difference just something to celebrate as in postmodern views of the social model, but is a specific variable with an objective reality, which can be evaluated in relation to an individual's functions and capabilities" (Terzi, 2004 in Reindal 2010, p. 3). Veck (2007, p. 8) suggests: "In tenderness, a listener may move from thinking of a speaker's differences as deficiency and come to consider the ways in which these differences might make a difference to them. At this moment, the speaker becomes entirely and unalterably connected to the world, for they have influenced the ways others act within the world and have thereby – in however small a way – contributed to it."

Listening to the story of parents, they tell us that the relation with the child is often dominated by what is wrong with the child: the disease, the deficit and the developmental possibilities. The child, much more than all these labels, only becomes visible later on when the mothers and fathers are able to connect with the child. They experience through contact that the child with his/her disability is a unique and irreplaceable creature and above all their own child (Isarin, 2005b). When we meet parents for the first time, they have to tell us about the birth of their son/daughter, about when they realized that there were problems and about everything their child is able to do. These are all very concrete and small critical incidents that are very important in the emotional bond with the child. At the same time parents have their 'files' with them, they are well equipped with all kinds of testing, medical reports, therapists opinions about the level and prognoses for the future. Ferguson (2003, p. 138) writes about his son Ian, who is 28 years old at that time: "Over the years he has collected a variety of labels that supposedly specify what those disabilities are: severe mental retardation, spastic quadriplegia,

developmental disabilities. Predictably, the educational and adult service systems involved in his life have given labels only to his perceived limitations; there have been no clinical diagnoses for his mixture of odd talents and personal quirks that are the main images I have of him now.” Insights from activists and their allies take us beyond taken-for-granted truths to journeys of discovering new, complex and plural knowledge(s) and meanings (Goodley and Van Hove, 2005).

Dialogue

Rinaldi puts dialogue very central in pedagogy. For her dialogue is much more than a method, she speaks about a ‘transformational dialogue’ (Rinaldi, 2006, p. 76) where the relation is subjected to change. Dialogue is of absolute importance. “It is an idea of dialogue (...) as a process of transformation where you lose absolutely the possibility of controlling the final result. And it goes to infinity, it goes to the universe, you can get lost. And for human beings nowadays, and for women, particularly, to get lost is a possibility and a risk, you know?” (Rinaldi, 2006, p. 184). In this dialogue, based on listening, as a teacher you have to participate together with the child, “entering a space together where both teacher and child are actively listening and trying to construct meaning out of the situation” (Dahlberg & Moss, 2005, p. 101).

Learning from Levinas exactly opens up a dialogical space where pedagogy “becomes – or remains – an event rather than being a pre-programmed process. Learning, in his view, is not about the acquisition of knowledge or truth. It is about response and responding. Similarly pedagogy is not about handing down truths to the next generation, but about creating opportunities for children (...) to respond and as a result come into presence” (Biesta, 2008, p. 206). Bergkamp and Alerby (2006, p. 6) follow Levinas with his emphasis on openness as a condition for real communication: “In this openness the responsibility for the Other reveals itself (Levinas, 1989) and here the ability to care can be a helpful way to keep openness. Noddings (2002) means that this dialogue draws the attention to the Other, not just the topic of the conversation. (...) In the dialogue we can also talk about the intentions of our actions and reflect upon the effects of our actions. Noddings (2002) states that this ‘... is our way of being in relation’ (p 19).”

Dialogue is also the groundwork for Paulo Freire (1970). 'True dialogue' is where both parties speak and listen. Freire sees that a human being is through dialogue connected with other people and the surrounding world. Being in the world is not seen as a static status, it is a continuous process of becoming, a continual coming into presence (Ferguson, 1995 in McPhail, 2001). A subject can transcend his/her own borders by communicating. This is not the same as talking; it is all about exchanging in relationship. Ludo Schoeters, the president of the self-advocacy movement in Flanders, makes clear that exchange for him is about support and guidance. It shifts from one person to another, it goes back and forth, over and over again. This exchange can only take place in a complex interplay between human beings and their environment.

Dialogue according to Freire is horizontal dialogue. He wants to step out the vertical power relation by giving each member of society the opportunity to speak and act. What is very important when we try to say something is, first, to try to be with the people, not to assume an attitude which implies that we are more above the people than with the people (Freire 1985 in Bruss & Macedo, 1985, p. 8). Freire is convinced that conscious human beings have the ability to think creatively and through dialogue can transform their daily reality instead of adjusting and accommodating to it.

We can often find this dialogue in the teams around the children in inclusive education. Teachers, parents, support workers and therapists who work closely with the child come together. They contribute their stories and perspectives about what is happening in class and at home. They share their observations, exchange about what is going well, talk about their worries and feel at ease to ask questions. They built upon each other's information, insights, advice and suggestions to come up with new ideas. It is a creative, on-going process engaged by a group who knows the child very well. Sofie's mother talks about people 'who love her child'. It is through this process of action and reflection, praxis for Freire, that we can shape together an individual trajectory for the child and his/her participation in class.

7.5. Political engagement

“Pedagogy like school is not neutral. It takes sides, it participates in deep and vital ways in the definition of this project whose central theme is not mankind, but his relations with the world, his being in the world, his feeling of interdependence with what is other than himself. So pedagogy implies choices and choosing” (Rinaldi, 2006, p. 10). What kind of education do we want? What is important for our children as they grow up? How do we think about and look at children? What do we mean with ‘inclusion’, ‘participation’, ‘support’, ‘disability’ and ‘care’? What is the role of ‘parents’ and ‘teachers’ in education? What are the tasks of a school in our society? Biesta (2009, p. 1) agrees: “Questions about education always raise normative issues and therefore always require value judgments about what we consider desirable. We do not expect one answer – on-going discussions about purpose and directions.” Our pedagogical work can never be separated from ethics and politics.

For Levinas, utopia can provide us with guidance in these difficult discussions. “Utopian thought both provokes and enables radical critique of the status quo – through confrontation by imagination of whatever exists. And it gives direction for future change, by the exploration of imagination of new modes of human possibility that enable us to reinvent the future. It both deconstructs the present and reconstructs the future. It provides a provocation to politics, both major and minor, through the act of thinking differently” (Dahlberg & Moss, 2005, p. 177). We would like to look at education that way. We want every child to feel welcome at school and every parent to be able to choose the school he/she wants for their children without a struggle. An inclusive society is something we strive for, it is not a state that we can measure: how included is the child?, how inclusive is the school/the teacher?... It is a process, a flow with ups and downs, with inclusive and exclusive moments. It goes together with the way we treat ‘difference’ in our society.

With pedagogues we want to invest in constant movement, a continuous becoming. Gust, the teacher of 4th grade is aware of that: “When I

finished my teacher training, I got the message that the certificate meant that I was capable to start. I took into account that I had to keep on learning. Education changes constantly. I have to keep on moving along. That is a challenge in our profession. For me, Senne was another opportunity to be aware of this challenge." In this way of looking at education and the role of teacher, the teacher preparation can play an important role. They prepare teachers not only in a technical way, but with profound respect for otherness and a deep sense of responsibility for the Other.

When we think about this kind of changes in education and society, I am aware that utopian thinking alone is not enough. "That needs also a willingness to act. Both Utopian thought and action are more likely to occur and flourish when certain conditions are present. (...) This means spaces where there is an openness to research and continuous reflection, critique and argumentation" (Dahlberg & Moss, 2005, p. 177). We can call those spaces 'loci of ethical practice', 'borderlands' or spaces 'in-between'. There we can on one hand critically discuss existing practices in education and on the other hand put the spotlight on new, modest and developing praxis where people engage in listening and experimentation.

When we think about a political engagement, it is not depending on an individual or several individuals. It is necessary to think in connections and movements in order to take steps in social change. We need to develop a coalitional consciousness (Sandoval, 2000). "The nature of this work is difficult and complex, you feel threatened to the core" (Naraian, 2011). The aim is to resist, "to resist to power, to resist to the intolerable, resist to fear and resist to shame, resist to the injustice of the present" (Pisters, 2009, p. 20). These micropolitical acts of resistance can give signs of hopes in this majoritarian jungle and provide slightly new perceptions of the world.

These reflections, discussions and actions cannot take place without people with a disability themselves. In my personal story, I recognize Sofie as my agent of change who helped me and gave me the possibility of becoming. I am convinced that we have "to invest in dialogue with those seeking to (self)empowerment and their politics of resilience" (Van Hove & Roets, 2000). "Situated knowledge(s) of individuals are crucial to

the capacity to engage in political struggle which is weakened if people feel that aspects of their experience, and of their sense of self, are alienated or denied by the terms and conditions of their struggle” (Thomas, 2001 in Peters & Gabel, 2004, p. 593). Children/adults with a disability and their families are the soul of disability studies, we have to recognize that over and over again and make it visible over and over again.

*Verzet begint niet met grote woorden
maar met kleine daden
zoals storm met zacht geritsel in de tuin
of de kat die de kolder in zijn kop krijgt
zoals brede rivieren
met een kleine bron
verscholen in het woud
zoals een vuurzee
met dezelfde lucifer
die een sigaret aansteekt
zoals liefde met een blik
een aanraking iets dat je opvalt in een stem
jezelf een vraag stellen
daarmee begint verzet

en dan die vraag aan een ander stellen*

*Resistance doesn't begin with big words
but with small actions
Like a storm with soft rustling in the garden
or a cat that's going crazy
Like broad rivers
with a small source
hidden in the wood
Like a sea of fire
with the same match
that one lights a cigarette
Like love with a glance
a touch
something that you notice in a voice
Posing yourself a question
that's how resistance starts

and posing that question to another*

(Remco Campert, 1929)

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Samenvatting

Het raamwerk voor dit doctoraat ligt binnen Disability Studies. Dit is een opkomend, interdisciplinair academisch veld dat kritisch de dynamische interactie onderzoekt tussen een beperking en de omgeving. Een beperking is een sociaal, cultureel, historisch en relationeel gegeven. Disability Studies brengt kritisch onderzoek samen met een politiek engagement om te streven naar verandering. Men vertrekt steeds vanuit de ervaringen en belichaming van een beperking bij de mensen zelf.

Ik ben gaan kijken naar kinderen met een beperking binnen inclusief onderwijs en de samenleving. Inclusie is een moeilijk en veelzijdig proces. Er zijn geen gemakkelijke antwoorden, geen voorgepakte en duidelijke trajecten. Inclusie kan op veel verschillende manieren geïnterpreteerd worden. De vlag van inclusie dekt de lading niet. Vandaar proberen we om het benaderen vanuit verschillende perspectieven, door de ogen van de verschillende betrokkenen.

Kinderen

Deze studie onderzoekt de beleving van kinderen die school lopen in het regulier onderwijs. Ik werkte met observaties en interviews van 15 kinderen tussen 5 en 17 jaar oud. We kunnen doorheen de analyse zien dat kinderen zich eigenlijk heel 'gewoon' gaan presenteren, als kinderen met heel alledaagse bezigheden, interesses en wensen. Ze zijn zich bewust van hun beperking(en), maar vertellen ons heel vaak hoe ze hiermee (proberen te) leven. Het is duidelijk dat school een belangrijk deel van hun leven is, ze vertellen vooral veel over de sociale activiteiten op school. Ondersteuning was voor veel kinderen positief omdat het betekende dat de participatie in de klas makkelijker werd, tegelijk werd ondersteuning op sommige momenten ook als hinderlijk ervaren. De kinderen hadden allemaal grote plannen en vooruitzichten voor de toekomst.

Ouders

In dit hoofdstuk introduceren we verschillende metaforen die we ontwikkeld hebben in de samenwerking met ouders binnen inclusief onderwijs. De reiziger, de strijder, de bruggenbouwer, de ontdekker, de leraar, Kuifje in Wonderland,... I wil vanuit deze metaforen proberen

omschrijven hoe ouders de confrontatie aangaan met de normaliserende praktijken binnen onze samenleving zowel binnen de dienstverlening van mensen met een beperking als onderwijs. Ouders kunnen gezien worden als ouders 'aan de rand', in een voortdurend proces van reflectie over hun leven samen met hun kind met een beperking.

Leraren

Leraar zijn is een belangrijke, spannende en veeleisende opdracht in onze samenleving. Het vraagt heel wat verantwoordelijkheid om kinderen en jongeren te laten opgroeien tot veelzijdige, mondige en kritische burgers. Daarbij wordt de leraar telkens voor nieuwe uitdagingen geplaatst. Op basis van de verhalen van 17 leraren keer ik terug naar centrale thema's en sleutelmomenten uit de dagelijkse klaspraktijk. De onzekerheden van leraren staan heel centraal in hun beleving. Leraren hebben veel angst en vragen rond het contact met het kind met een beperking en rond hun eigen competenties naar het les geven. Zij ervaren de sociale contacten met andere kinderen als dé grote meerwaarde van inclusief onderwijs. De communicatie en teamwerking met de mensen rondom het kind, is van cruciaal belang. Het geeft de leraren het gevoel dat ze er niet alleen voor staan.

Sofie en participatie

Ik focus mij hier op de zes jaar dat ikzelf als persoonlijk assistent een bijdrage geleverd heb aan het inclusieproces van Sofie, een meisje met een meervoudige motorische en communicatieve beperking. Ik probeer te beschrijven en na te gaan hoe haar participatie doorheen de lagere school vorm krijgt. Dit kan leiden tot een beter begrijpen van kinderen met ernstige beperkingen en de keuzes die hun families maken. Onderzoek met deze kinderen is tot nu toe vooral voorhanden binnen gesegregeerde settings. Binnen het onderzoek bij Sofie wil ik komen tot het (re)conceptualiseren van 'participatie', 'ontwikkeling' en 'leren'.

Mijn eigen positie

Deze terugblik schetst mijn eigen manier van 'wording' als Elisabeth en als onderzoeker. Het vertrekt vanuit wat ik geleerd heb als persoonlijk assistent binnen de klas, over het coachen van team binnen inclusief onderwijs naar mijn doctoraatsonderzoek dat terug valt op al deze praktijk. Het is mijn intentie om mijn betrokkenheid hier binnen open en

eerlijk te duiden zowel in zijn rijkdom als in de moeilijkheden die ermee gepaard gaan. Het leren in samen-werking met mensen en door te luisteren naar hun verhalen en verantwoordelijkheid te nemen binnen hun ondersteuning zijn heel belangrijke ingrediënten van mijn engagement. Om dit te doen zoek ik hulp bij concepten van Levinas en Deleuze & Guattari die mij helpen om mijn eigen positie te (re)construeren.

In de besluiten van deze doctoraatsthesis, heb ik een vijftal concepten centraal gesteld die voor mij als rode draden doorheen mijn werk geweven zijn.

- *Becoming*

Inclusief onderwijs kan beschouwd worden als een proces in voortdurende beweging dat steeds op zoek gaat om stratificatie en categorisatie uit te dagen om inperkingen te voorkomen. We kijken van nabij hoe kinderen met een beperking, hun ouders en leerkrachten in verbinding met elkaar op zoek gaan naar mogelijkheden om samen te leven en te leren.

- *Verlangen*

Verlangen wordt door Deleuze en Guattari gezien als een positieve en productieve kracht die ons voortdurend stuwt doorheen onze zoektocht om te beïnvloeden en beïnvloed te worden. We zoeken mogelijkheden om in voortdurende inter-afhankelijkheid elk ons anders-zijn een plaats te geven. Ik vertrek steeds vanuit het beeld van het 'competente kind' waarbij we samen op zoek gaan naar kansen en mogelijkheden om deze mogelijkheden te actualiseren binnen de omgeving van het gewoon onderwijs.

- *Ethische ontmoeting*

Levinas helpt me om de ontmoeting met de Ander te zien als een absolute en oneindige ver-antwoord-elijkheid naar die Ander. Een (ortho)pedagoog is voor mij een reisgezel die samen met kinderen en families op pad gaat zonder een vooraf gekende bestemming. We proberen mogelijkheden open te houden en zo min mogelijk restricties op te leggen zodat kinderen alle mogelijkheden krijgen om zich te ontplooien binnen de omgeving waar hun familie het meeste vertoeft. In

wat wij kunnen doen, zijn we heel erg afhankelijk van de Ander, die beroep op ons doet.

- *Luisteren*

De klas is een plaats van ontmoeting en Rinaldi schetst luisteren als een sociaal en relationeel proces waarbij we ons ten volle open stellen voor de kinderen en volwassenen waar we mee samen werken. Luisteren is een sensitiviteit die niet alleen met oren plaatsvindt, het werkt verbindend en poogt te begrijpen. Dit wordt gestuurd door het zoeken naar verlangen, onzekerheden en de 'inter-esses' van mensen in plaats van het voortdurend zoeken naar vooraf bepaalde antwoorden.

- *Politiek engagement*

Pedagogiek is niet neutraal. Het kiest partij en impliceert het maken van keuzes. Welk onderwijs willen wij? Hoe kijken wij naar 'participatie' en 'ontwikkeling'? Wat is belangrijk binnen onze samenleving waar we kinderen willen in opvoeden? Dit brengt een maatschappelijk debat teweeg dat voortdurend aan de gang blijft. Voor Levinas kan Utopie ons leiden doorheen zulke moeilijke discussies. Het geeft richting aan waar we in toekomst naartoe willen, het laat ons dromen en fantaseren over wat ze zouden willen zonder dat het onmiddellijk actueel aanwezig is. Het streven ernaar is echter heel erg belangrijk en vraagt een voortdurend zoeken naar sociale verandering. Het vraagt om dicht bij mensen te staan, erkenning te geven aan 'wie' ze zijn en wat ze willen en dit telkens opnieuw zichtbaar te maken.